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ABSTRACT

The purpose of the Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments (TRACES) Project was to provide technical assistance to state and multistate projects to improve the quality of existing placements and services for children with deaf-blindness. Seven major objectives guided project activities: assist projects to identify training/program needs and develop state technical assistance plans; provide projects with technical assistance to address training/program needs; develop a consultant pool of experts to plan and deliver technical assistance; disseminate information from project reports, research findings, and journal articles to the field; develop monographs that address topical issues and administrative functions in service delivery; provide technical assistance in preparing and submitting federally required data; and provide planning and support for project directors' meetings. This report contains an overview of major activities associated with each project objective, outcomes of each objective, and financial records. Appendices contain: (1) forms and meeting agendas used in administering the project; (2) a resource listing of consultants with an index by state and areas of experience; (3) a monograph by Anita C. Briggs and Rich Mulholland titled "Grant Writing Services for Children with Deaf-Blindness Program"; and (4) a monograph by Kathryn Wolff Heller and Cheryl Kennedy titled "Etiologies and Characteristics of Deaf-Blindness." Contains 41 tables. (JDD)

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ED 381 936

# Final Report

for

# Technical Assistance to State and Multi-State Services for Children with Deaf-Blindness Projects

October 1, 1990 - September 30, 1993

Agreement #: HO25C00001

*Submitted by:*

Traces

TEACHING RESEARCH ASSISTANCE TO CHILDREN AND YOUTH EXPERIENCING SENSORY IMPAIRMENTS

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EC 303 882

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**FINAL REPORT**
**for**

**Technical Assistance to**
**State and Multi-State**
**Services for Children with Deaf-Blindness**
**Projects**

**October 1, 1990 - September 30, 1993**

**Agreement #: H025C00001**

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# INTRODUCTION

The purpose of the Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments Project (TRACES Project) was to provide technical assistance to state and multi-state 307.11 grantees to improve the quality of existing placements and services for children with deaf-blindness. The TRACES Project was designed to provide a national effort of training/technical assistance to 307.11 grantees who serve this heterogenous population of infants, toddlers, children and youth who range from very high levels of capabilities and performance to much lower levels of functioning. Technical assistance was provided to enable change across four dimensions: individual enhancement, program/system component (singular) improvement, program/system components (multiple), and systems change.

To manage the project, the states and territories were divided into geographical areas and the geographical areas were further divided into regions. Each geographical area represented a cluster of states and territories. As can be seen in the organizational schematic illustrated in Figure 1, there are three geographic areas. Area I is made up of states and territories in the Western region, Area II is made up of states in the North Central and Northeast regions, and Area III is made up of states and territories in the South Central and Southeast regions. This organizational structure is operated by a consortium of individuals located at major universities or higher education facilities. The consortium membership is contained in Figure 2.

## Purpose of Report

This manuscript is the final report for the TRACES Project for the period October 1, 1990 to September 31, 1993. During this period seven major objectives guided the project activities and led to specific outcomes or results. The objectives are:

1. To assist state and multi-state projects for deaf-blindness and/or their subcontractors to identify training/program needs and develop state technical assistance plans.

2. To provide state and multi-state projects for deaf-blindness and/or their subcontractors with technical assistance to address training/program needs.

3. To develop a consultant pool of experts to plan and deliver technical assistance to address training/program needs.

4. To select quality project reports, research findings, peer reviewed journal articles, and other materials pertaining to the provision of services to children with deaf-blindness, and to disseminate this information to the field in response to requests from state educational agencies.

5. To develop a series of monographs that address topical issues of concern and administrative functions in the field of service delivery for children with deaf-blindness.

6. To provide technical assistance to the 34 CFR 307.11 grantees in their preparation and submission of data required under Paragraph (C) (2) of Section 622 of the Individuals with Disabilities Education Act.

7. To provide planning, assistance and managerial support for programmatically substantive annual meetings in Washington, D.C. for directors of projects serving children with deaf-blindness.

Section I of this report contains an overview of the major activities associated with each project objective and the outcomes or results of each project objective. Section II contains the financial records.

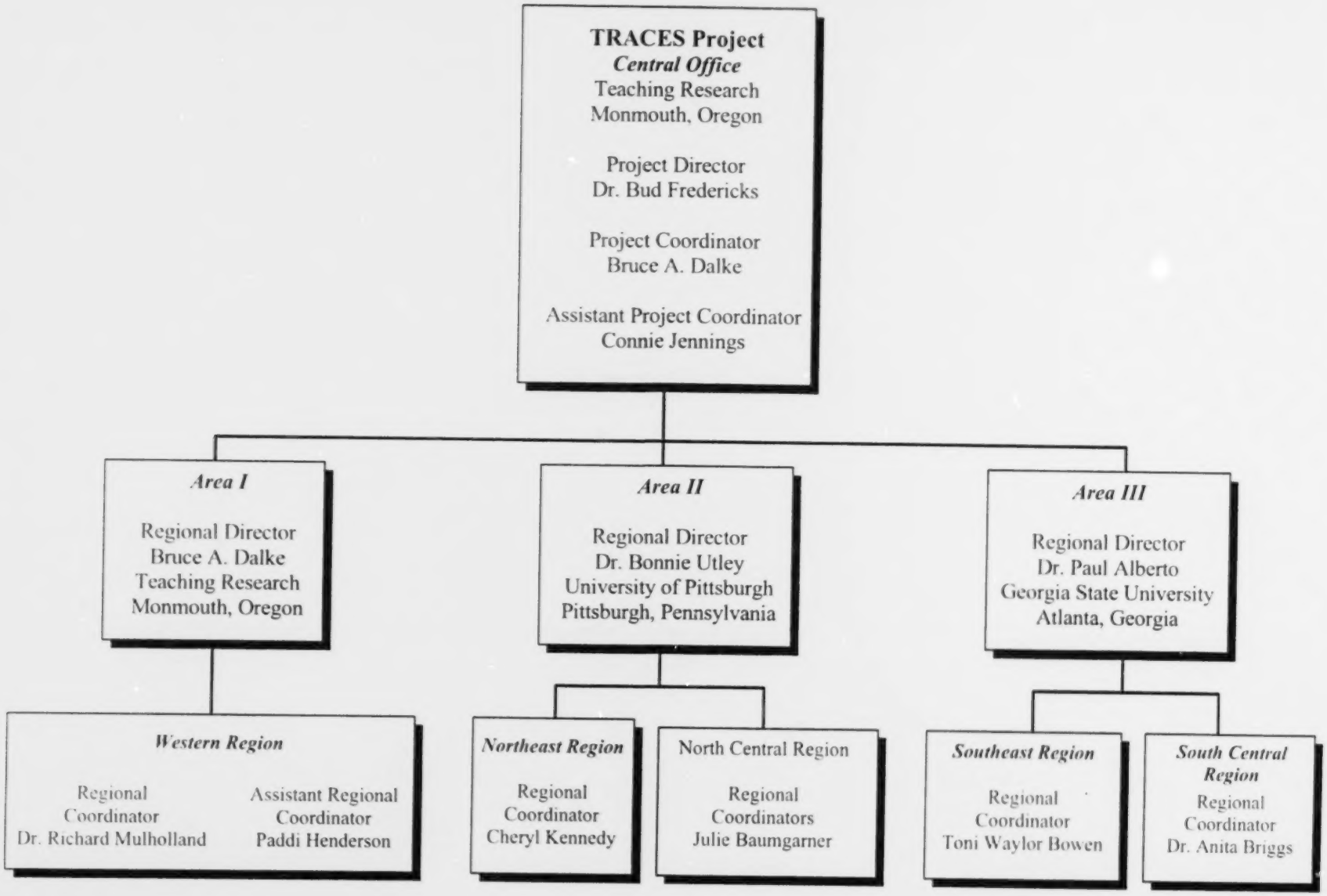


**Figure 2 TRACES Consortium organization**

# SECTION I

# OVERVIEW AND OUTCOMES

# of

# PROJECT OBJECTIVES

**Objective 1: To assist state and multi-state projects for deaf-blindness and/or their subcontractors to identify training/program needs and develop state technical assistance plans.**

The purpose of the TRACES Project during the time period of this report was to assist State and multi-State Services to Children with Deaf-blindness projects (34 CFR 307.11 grantees) in more effectively providing appropriate educational and related services to children with deaf-blindness. As stated in 34 CFR Part 307.11(a)(1), the grantee is responsible to give the first priority to "children with deaf-blindness to whom States are not obligated to make available a free appropriate public education under part B of the Individuals with Disabilities Education Act and to whom the State is not providing those services under some other authority". The second priority, as stated in 307.11(a)(2), is providing "technical assistance to public and private agencies, institutions, and organizations providing early intervention, educational, transitional, vocational, early identification, and related services to children with deaf-blindness".

To fulfill the regulations which are based on proven effective educational practices, many states had to enhance/modify their service delivery system for children with deaf-blindness. Such modifications could only occur if change activities were facilitated and directed at adopting and implementing effective service delivery practices, and fostering appropriate intra-agency and inter-agency collaboration.

The TRACES Project focused on technical assistance to bring about change at all levels of service delivery (e.g., family, building, LEA, state). With assistance from the TRACES technical assistance project staff, the State or multi-State 307.11 project staff identified the major change activities that, when completed, resulted in more comprehensive and appropriate options available along the continuum of services for children with deaf-blindness. This was accomplished through utilization of a needs assessment developed by TRACES staff. A copy of the needs assessment that was used by the TRACES Project for 1990-93 is contained in Appendix A.

After the needs were generated and prioritized, a state technical assistance plan outlining

how the needs were to be addressed was developed. The needs assessment form and the state technical assistance plan were completed prior to the development and conduct of technical assistance activities. The state plan form is also contained in Appendix A.

**Evaluation**

1. Priority technical assistance needs based on two criteria are identified: a) activities that assist states to comply with the federal regulations for single and multi-state deaf-blind projects and b) activities that promote the education of children with deaf-blindness in the least restrictive settings.

2. A state technical assistance plan that contains the area of technical assistance (e.g., program development, family involvement, communication), the goal/objective of the technical assistance, timeline for completing the goal/objective, and persons who will be responsible is developed.

**Outcome/Results**

There were a total of 54 states and territories that were entitled to technical assistance during the 1990-1993 time period under the provisions of the cooperative agreement. All states and territories completed the needs assessment form and all developed state technical assistance plans with the TRACES Coordinators.

Needs assessment and state plan information for individual states and territories within geographical areas can be found in Tables 1 through 5.

Table 1

**Technical assistance needs assessment information and state plans for the western geographical area**

| | States | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Alaska | Colorado | Idaho | Montana | Oregon | Utah | Washington | Wyoming |
| Needs Assessment Information | | | | | | | | |
| 1990-91 | + | + | + | + | + | + | + | + |
| 1991-92 | + | - | + | + | + | + | + | - |
| 1992-93 | + | + | + | + | + | + | + | + |
| State Plan | | | | | | | | |
| 1990-91 | + | + | + | + | + | + | + | + |
| 1991-92 | + | + | + | - | + | + | + | - |
| 1992-93 | + | + | + | - | + | + | + | + |

11

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**Table 1 Continued**

| States and Territories | | | | | | |
|---|---|---|---|---|---|---|
| | Arizona | California | Hawaii | Nevada | New Mexico | Pacific Basin |
| Needs Assessment Information | | | | | | |
| 1990-91 | + | + | + | + | + | + |
| 1991-92 | + | + | - | + | + | - |
| 1992-93 | + | + | - | + | + | + |
| State Plan | | | | | | |
| 1990-91 | + | + | - | + | + | + |
| 1991-92 | + | + | + | + | - | - |
| 1992-93 | - | - | + | + | - | - |

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Table 2

**Technical assistance needs assessment information and state plans for the north central geographical area**

| | States | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Illinois | Indiana | Iowa | Kansas | Michigan | Minnesota | Missouri | Nebraska | North Dakota | South Dakota |
| Needs Assessment Information | | | | | | | | | | |
| 1990-91 | + | + | + | + | + | + | + | + | + | + |
| 1991-92 | - | + | + | + | + | + | + | + | + | + |
| 1992-93 | + | + | + | + | + | + | + | + | + | + |
| State Plan | | | | | | | | | | |
| 1990-91 | + | + | + | + | + | + | + | + | + | + |
| 1991-92 | - | + | + | + | + | + | + | + | + | + |
| 1992-93 | + | + | + | + | + | + | + | + | + | + |

13

Table 3

**Technical assistance needs assessment information and state plans for the northeast geographical area**

| | States | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Connecticut | Delaware | Maine | Massa-chusetts | New Hampshire | New Jersey | New York | Ohio | Pennsylvania | Rhode Island | Vermont | Wisconsin |
| Needs Assessment Information | | | | | | | | | | | | |
| 1990-91 | + | + | + | + | + | + | + | + | + | - | + | + |
| 1991-92 | - | + | - | - | - | - | - | + | + | + | - | + |
| 1992-93 | + | - | + | + | + | + | + | + | + | + | + | + |
| State Plan | | | | | | | | | | | | |
| 1990-91 | + | + | + | + | + | + | + | - | + | - | + | + |
| 1991-92 | + | + | + | + | + | + | - | + | + | + | + | + |
| 1992-93 | + | - | + | + | + | + | + | + | + | + | + | + |

Table 4

**Technical assistance needs assessment information and state plans for the south central geographical area**

| | States | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Alabama | Arkansas | Florida | Kentucky | Louisiana | Mississippi | Oklahoma | Tennessee | Texas |
| Needs Assessment Information | | | | | | | | | |
| 1990-91 | + | + | + | + | + | + | + | - | + |
| 1991-92 | - | - | - | - | - | - | - | - | - |
| 1992-93 | + | + | + | + | + | + | + | + | + |
| State Plan | | | | | | | | | |
| 1990-91 | + | + | + | + | + | + | + | - | + |
| 1991-92 | + | + | + | + | + | + | + | + | + |
| 1992-93 | + | + | + | + | + | + | + | + | + |

Table 5

**Technical assistance needs assessment information and state plans for the southeast geographical area**

| | States | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Georgia | Maryland | North Carolina | Puerto Rico | South Carolina | Virgin Islands | Virginia | Washington DC | West Virginia |
| Needs Assessment Information | | | | | | | | | |
| 1990-91 | + | + | + | + | + | + | + | + | + |
| 1991-92 | - | - | - | - | - | - | - | - | - |
| 1992-93 | + | + | + | + | + | + | + | + | + |
| State Plan | | | | | | | | | |
| 1990-91 | + | + | + | + | + | + | + | + | + |
| 1991-92 | + | + | + | + | + | + | + | + | + |
| 1992-93 | + | + | + | - | + | - | + | + | + |

**Objective 2: To provide state and multi-state projects for deaf-blindness and/or their subcontractors with technical assistance to address training/program needs.**

After the technical assistance needs were identified and state plans completed, specific technical assistance agreements were developed and implemented (see Figure 3 for a sample of the agreement form that was used for 1990-93). Technical assistance was tailored to meet the needs of the state or multi-state program in bringing about change within systems, or components of systems, (e.g., statewide plan for service delivery, community based instruction planning and implementation) and was available in a variety of formats (e.g., on-site consultation, inservice sessions with follow-up). In all cases, technical assistance was aimed at either directly or indirectly impacting the lives of children who are deaf-blind and their families.

Although technical assistance was designed to meet individual needs of states, technical assistance also was designed to improve current services with the intent to promote the movement of children and youth in restricted settings to integrated, less restrictive settings, and/or improve the quality of services provided in these integrated, less restrictive settings.

There were several sequential activities that took place prior to the actual conduct of technical assistance activities (e.g., develop request/agreements for technical assistance, determine costs, obtain consultants). Once the development activities took place, then technical assistance activities began.

**Evaluation**

The effectiveness of technical assistance was evaluated across four levels.

1. Consumer Satisfaction: The extent to which technical assistance recipients are satisfied with specific activities (e.g., workshops) and the overall assistance they received (e.g., contractual experiences, expertise of consultant). The measures will be administered after various activities have taken place. Satisfaction with the overall project will be evaluated after a technical assistance agreement is completed.

# TRACES PROJECT - TA Agreement Form

| SFY | REG | TA # | | STATE | | INV # | | FFY |
|---|---|---|---|---|---|---|---|---|
| 5 | | | | | | 0 | 1 | 5 |

TA Format: _____

TA Content: _____

Consultant(s): _____

Project/Program/Person: _____

Goal: _____

Focus of TA/Unit of Analysis: _____

Key Service Being Addressed: _____

Administrative Level(s) Being Addressed: _____

Target(s) for Change: _____

Others Contributing to the Provision of the TA: _____

☆ Recommends Materials for Production/Dissemination

| | AGE/N | | | | | Recipients | N | LEVELS | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | I | P | E | JH/HS | A | | | I | II | III | IV |
| D/B | | | | | | | | | | | |
| SD | | | | | | | | | | | |
| Other | | | | | | | | | | | |
| Indirect | | | | | | | | | | | |

| TA OBJECTIVES | TA ACTIVITIES | TIMELINES | EVALUATION PLAN |
|---|---|---|---|
| | | | Level of Evaluation: _____<br>Design: _____<br>Measure(s): _____<br>Activity: |

Signature: _____ Date: _____ Signature: _____ Date: _____

(TRACES Regional Director) (Grantee/State Coordinator)

TAAFORM.894

## TA Agreement Form - Continued

Page _____ of _____

| SFY | REG | TA # | | STATE | | INV # | | FFY |
|---|---|---|---|---|---|---|---|---|
| 5 | | | | | | 0 | 1 | 5 |

| TA OBJECTIVES | TA ACTIVITIES | TIMELINES | EVALUATION PLAN |
|---|---|---|---|
| | | | Level of Evaluation: _____<br>Design: _____<br>Measure(s): _____<br>_____<br>Activity: |
| | | | Level of Evaluation: _____<br>Design: _____<br>Measure(s): _____<br>_____<br>Activity: |
| | | | Level of Evaluation: _____<br>Design: _____<br>Measure(s): _____<br>_____<br>Activity: |

2. Knowledge/Skill Acquisition: The extent to which technical assistance recipients gain knowledge/skills attributed to the technical assistance. The measurement design will depend on the type of technical assistance involvement and/or the specific technical assistance activities. The design options include: pre-post immediate, pre-post delayed, post immediate, and post delayed.

3. Knowledge/Skill Implementation: The extent to which technical assistance recipients apply (i.e., use) the knowledge/skills they gain. Two or more implementation measures will be used. The measurement design will depend on the type of technical assistance involvement and/or the specific technical assistance activities. The design options include: pre-post, pre-probe(s)-post, probe(s)-post, and post.

4. Child/Student Change: The extent to which deaf-blind and/or severely handicapped individuals are affected by the technical assistance will be dependent on the type of technical assistance involvement and/or the specific technical assistance activities. The design options include: Pre-post, pre-probe(s)-post, and post.

**Outcome/Results**

Based on the needs assessment information and the state plans a number of technical assistance requests were made and technical assistance agreements formalized. Of the 54 states and territories that completed technical assistance state plans, all 54 states and territories participated in the formal technical assistance agreement process and received technical assistance during the three year project period. In addition, twenty five formal agreements were written involving multi-state regional activities. Two hundred eighty seven (287) total technical assistance agreements were completed during the 1990-93 period. The states that did not participate in the agreement process and receive subsequent technical assistance during any one year elected not to do so. A technical assistance agreement usually represented one particular technical assistance activity or site or program.

The number of formal technical assistance agreements for the individual states and territories within geographic areas can be found in Tables 6 through 10.

The impact or effectiveness of technical assistance was evaluated across four levels: 1) consumer satisfaction, 2) knowledge/skill acquisition, 3) knowledge/skill implementation, and 4) child/student performance change. The first level pertains to the extent to which recipients are

Table 6

**Formal technical assistance agreements for the western geographical area**

| | States | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Alaska | Colorado | Idaho | Montana | Oregon | Utah | Washington | Wyoming |
| Number of Formal Technical Assistance Agreements | | | | | | | | |
| 1990-91 | 2 | 2 | 3 | 1 | 1 | 3 | 8 | 1 |
| 1991-92 | 3 | 1 | 4 | 0[1] | 1 | 2 | 1 | 1 |
| 1992-93 | 2 | 1 | 4 | 1 | 3 | 2 | 1 | 2 |

[1] Did not request Formal Technical Assistance.

**Table 6 Continued**

| States and Territories | | | | | | | |
|---|---|---|---|---|---|---|---|
| | Arizona | California | Hawaii | Nevada | New Mexico | Pacific Territories | Regional |
| Number of Formal Technical Assistance Agreements | | | | | | | |
| 1990-91 | 1 | 7 | 1 | 4 | 2 | 2 | 1 |
| 1991-92 | 2 | 3 | 1 | 4 | 0[2] | 2 | 4 |
| 1992-93 | 1 | 4 | 1 | 2 | 3 | 2 | 6 |

[2] Did not request formal technical assistance.

[1] Did not request Formal Technical Assistance.

Table 7

**Formal technical assistance agreements for the north central geographical area**

| | States | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Illinois | Indiana | Iowa | Kansas | Michigan | Minnesota | Missouri | Nebraska | North Dakota | South Dakota | Regional |
| Number of Formal Technical Assistance Agreements | | | | | | | | | | | |
| 1990-91 | 2 | 1 | 2 | 2 | 3 | 2 | 2 | 3 | 2 | 1 | 0[3] |
| 1991-92 | 0[3] | 0[3] | 1 | 2 | 1 | 2 | 2 | 3 | 1 | 1 | 2 |
| 1992-93 | 0[3] | 2 | 3 | 2 | 2 | 1 | 2 | 1 | 1 | 2 | 2 |

[3] Did not request Formal Technical Assistance.

Table 8

**Formal technical assistance agreements for the northeast geographical area**

| | States | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Connecticut | Delaware | Maine | Massachu-setts | New Hampshire | New Jersey | New York | Ohio | Pennsyl-vania | Rhode Island | Vermont | Wisconsin | Regional |
| Number of Formal Technical Assistance Agreements | | | | | | | | | | | | | |
| 1990-91 | 1 | 1 | 1 | 1 | 1 | 2 | 2 | 1 | 1 | 0[4] | 1 | 1 | 0[4] |
| 1991-92 | 1 | 1 | 1 | 1 | 1 | 1 | 0[4] | 1 | 1 | 1 | 3 | 1 | 1 |
| 1992-93 | 2 | 1 | 2 | 1 | 2 | 2 | 1 | 1 | 1 | 1 | 1 | 1 | 2 |

[4] Did not request Formal Technical Assistance.

Table 9

**Formal technical assistance agreements for the south central geographical area**

| | States | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Alabama | Arkansas | Florida | Kentucky | Louisiana | Mississippi | Oklahoma | Tennessee | Texas | Regional |
| Number of Formal Technical Assistance Agreements | | | | | | | | | | |
| 1990-91 | 1 | 1 | 2 | 2 | 1 | 1 | 1 | 0[5] | 2 | 2 |
| 1991-92 | 1 | 2 | 1 | 3 | 2 | 1 | 1 | 1 | 1 | 1 |
| 1992-93 | 1 | 2 | 2 | 3 | 1 | 2 | 1 | 1 | 3 | 1 |

[5] Did not request Formal Technical Assistance.

Table 10

**Formal technical assistance agreements for the southeast geographical area**

| | States | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Georgia | Maryland | North Carolina | Puerto Rico | South Carolina | Virgin Islands | Virginia | Washington DC | West Virginia | Regional |
| Number of Formal Technical Assistance Agreements | | | | | | | | | | |
| 1990-91 | 4 | 2 | 3 | 1 | 1 | 1 | 2 | 1 | 3 | 1 |
| 1991-92 | 1 | 1 | 1 | 1 | 1 | 1 | 2 | 1 | 1 | 1 |
| 1992-93 | 1 | 2 | 1 | 1 | 1 | 2 | 1 | 0[6] | 2 | 1 |

[6] Did not request Formal Technical Assistance

satisfied with the technical assistance they received. The second and third levels concern the acquisition and application respectively, of knowledge and/or skills gained as a result of technical assistance. The last level pertains to the extent to which deaf-blind individuals are affected by the technical assistance.

The dependent variables (i.e., satisfaction, skill/knowledge acquisition and implementation, and individual performance change) were measured using both required and optional dependent measures and/or instruments. The instruments used to measure satisfaction (e. g., McCallon Scale and the Technical Assistance Evaluation form) were standard measures. Because the nature of the different technical assistance activities varied greatly (e.g., different topical areas, different training needs and objectives, differences in target populations), the measure/instrument selection used to measure skill/knowledge acquisition and implementation, and performance change was left to the discretion of the project consultant hired to deliver the technical assistance and the Regional Coordinator.

Each technical assistance agreement (i.e., the technical assistance delivery objectives and activity plans) was evaluated across one or more of the evaluation levels. The particular levels that were addressed in the evaluation activities were determined by the technical assistance goals and objectives, the specific activities, and the identified dependent variables.

Following are the results from the project evaluation efforts for the 1990-93 period.

**Outcome/Results**

The data from the various dependent measures were analyzed using descriptive statistics (i.e., frequency, percent, mean, and standard deviation). For most analyses the total number of cases vary due to certain uncontrollable or legitimate circumstances (e.g., certain measures were not used, not all evaluation levels were addressed in all technical assistance agreements). The evaluation results will be presented for each level of evaluation, as well as a description of the overall project and/or the technical assistance agreements and activities that occurred. The

resulting evaluation data will be presented in tables in this section of the report and some of the data will be presented in the appendices.

**Project Description Results**

The evaluation data were organized and analyzed according to selected factors that related to the independent variable (i.e., technical assistance). Because technical assistance activities were designed based on individual training needs, there was variance between the different agreements and activities. In order to examine the results for the overall project, data from the different technical assistance agreements had to be organized into some common element. Technical assistance delivery format was one common element that related to the independent variable and provided a way to group the data from the various activities. The delivery formats used to group the data for the analyses are: group instruction; group instruction with on site consultation; and on site consultation, meeting, product/materials development, telephone conferences, and dissemination activities.

The data were also grouped, analyzed, and interpreted according to the focus or type of technical assistance, or the unit of analysis (i.e., individual, system component, system components, whole system). Some analyses were also conducted according to key service addressed (direct service, technical assistance, project management), administrative level (state/multi-state, region, local, building, family, individual), and targets for change (e.g., philosophy, policy, programs/services, effective practices, etc.).

The focus of the technical assistance agreement. There are four foci or analyses options that identify the nature of anticipated change due to a technical assistance effort. The four options are: individual change, system component change, system components change, and system change. In each case, the technical assistance is designed to ultimately bring about change at the individual child level.

Table 11

**Level of Impact on Target Population**[1]

| | 1990-91 | | | 1991-92 | | | 1992-93 | | |
|---|---|---|---|---|---|---|---|---|---|
| | Direct | Indirect | Total | Direct | Indirect | Total | Direct | Indirect | Total |
| Infant | 8 | 191 | 199 | 6 | 149 | 155 | 14 | 100 | 114 |
| Preschool | 22 | 371 | 393 | 20 | 296 | 316 | 24 | 219 | 243 |
| Elementary | 60 | 821 | 881 | 69 | 670 | 739 | 90 | 544 | 634 |
| Jr./Sr. High School | 59 | 1521 | 1580 | 99 | 700 | 799 | 74 | 458 | 532 |
| Adult | 1 | 236 | 237 | 8 | 286 | 294 | 23 | 311 | 334 |
| TOTAL | 150 | 3140 | 3290 | 202 | 2134 | 2336 | 225 | 1778 | 2003 |

[1] Numbers of children who are deaf-blind for which population data was reported.

Target Population Results. The target population data can be found in Table 11. A total of 7,629 individuals were involved in and/or directly or indirectly affected by technical assistance over the three year period from 1990-93. Of these 7,629 individuals, 577 were directly and immediately impacted through on-site technical assistance. The remaining 7,052 were indirectly impacted through resulting changes in programs and systems designed to provide services to children who are deaf-blind.

Participant Results. Table 12 presents the number of professionals, paraprofessionals, and parents who participated in the various technical assistance activities for which participant data was reported. During the three year project period (1990-1993) there were a total of 6,395 participants in technical assistance activities. The largest number of participants was in the 1990-91 project year due to the large number of group instruction/workshop type of technical assistance activities. Teachers/paraprofessionals and parent/family members were the most common participants during the three years. There were 2,462 teachers and/or paraprofessionals who participated in technical assistance activities and 1,293 parents/family members who were involved in activities. Of the 6,395 participants for which participant data was reported, 1,145 were unidentified.

Results According to Primary Delivery Format and Content. Table 13 presents the primary technical assistance delivery formats and the number and percent of technical assistance activities that occurred per format during the three project years. Of the cases during the 1990-93 period that reported delivery format data, the most common formats used were meetings/retreats (n=94), group instruction/workshops (n=53), and group instruction with follow-up on-site consultation (n=52).

Technical assistance agreements were geared to certain training needs that focused on certain topical or content areas (e.g., communication-interaction skills, community-based curricula approaches, behavior management usages, family education and

Table 12

**Technical Assistance Participants**

| Participants | 1990-91 | | 1991-92 | | 1992-93 | |
|---|---|---|---|---|---|---|
| | Number[1] of Cases | N | Number of Cases | N | Number of Cases | N |
| Parents | 31 | 898 | 13 | 99 | 19 | 296 |
| Teachers/Paraprofessionals | 53 | 1619 | 24 | 372 | 33 | 471 |
| Administrators | 25 | 181 | 9 | 18 | 10 | 16 |
| Consultants | 19 | 121 | 12 | 29 | 6 | 14 |
| Psychologists/Therapists | 15 | 291 | 7 | 104 | 8 | 63 |
| State/Local Agency Personnel | 16 | 141 | 14 | 139 | 7 | 45 |
| 307.11 Personnel | 20 | 71 | 32 | 102 | 38 | 160 |
| Unidentified | 0 | 0 | 14 | 410 | 21 | 735 |
| Total | 87 | 3322 | 70 | 1273 | 90 | 1800 |

[1] The number of cases or technical assistance agreements for which there were participant data.

Table 13

Primary Technical Assistance Delivery Formats

| Format | 1990-91 | | 1991-92 | | 1992-93 | |
|---|---|---|---|---|---|---|
| | Number | Percent | Number | Percent | Number | Percent |
| Group Instruction/ Workshop | 31 | 34.4 | 7 | 9.1 | 15 | 16.1 |
| Group Instruction/ Workshop with On-Site Follow-up | 17 | 18.9 | 22 | 28.6 | 13 | 14.0 |
| On-Site Consultation | 14 | 15.6 | 10 | 13.0 | 17 | 18.3 |
| Meeting/Retreat | 25 | 27.8 | 32 | 41.6 | 37 | 39.8 |
| Product Development | 1 | 1.1 | 3 | 3.9 | 11 | 11.8 |
| Dissemination Activities | 0 | | 1 | 1.3 | 0 | |
| Telephone | 2 | 2.2 | 2 | 2.6 | 0 | |
| Total | 90 | 100.0 | 77 | 100.0 | 93 | 100.0 |

Table 14

**Major Technical Assistance Content Areas: Formal Technical Assistance**

| Content Areas | 1990-91 | 1991-92 | 1992-93 |
|---|---|---|---|
| 1. Instruction: Systematic | 8 | 4 | 1 |
| 2. Instruction: Sensory Adaptation | 1 | 2 | 0 |
| 3. Instruction: Functional Activity Programs | 0 | 0 | 0 |
| 4. Instruction: Instructional Environment | 7 | 8 | 11 |
| 5. Instruction: Adaptive Technology | 2 | 1 | 0 |
| 6. Integration/LRE | 5 | 4 | 6 |
| 7. Grant Development | 1 | 13 | 4 |
| 8. Child Find | 9 | 7 | 14 |
| 9. Personnel Preparation System: Inservice | 2 | 4 | 2 |
| 10. Personnel Preparation System: Preservice | 2 | 1 | 0 |
| 11. Transition: Vocational | 7 | 3 | 8 |
| 12. Transition: Residential | 12 | 4 | 9 |
| 13. Transition: Early Childhood | 2 | 0 | 1 |
| 14. Behavior Management | 3 | 2 | 2 |
| 15. Communication | 9 | 11 | 10 |
| 16. Interagency Collaboration | 3 | 6 | 3 |
| 17. Sensory Assessment | 3 | 4 | 12 |
| 18. Programmatic Assessment | 2 | 8 | 13 |
| 19. Early Intervention | 3 | 3 | 5 |
| 20. Recreation | 1 | 0 | 0 |
| 21. Orientation and Mobility | 2 | 1 | 5 |
| 22. Complex Health Needs | 1 | 0 | 3 |
| 23. Family/Parent Needs | 6 | 7 | 15 |
| 24. Vocational Training | 0 | 1 | 0 |
| 25. Deaf-Blind Etiology | 0 | 3 | 0 |
| 26. System Change | 0 | 3 | 5 |
| 27. Technical Assistance Provision System | 5 | 3 | 9 |
| 28. Best Practices Generally | 2 | 4 | 7 |
| 29. Futures Planning | 0 | 3 | 4 |
| 30. Evaluation | 0 | 2 | 8 |
| 31. Strategic Planning | 0 | 2 | 0 |
| 32. Needs Assessment | 0 | 2 | 1 |
| 33. Collaborative Teaming | 0 | 3 | 1 |
| 34. Creative Problem Solving | 0 | 3 | 0 |
| 35. Consumer Support Network | 0 | 0 | 1 |
| 36. Resource Library | 0 | 0 | 1 |

Table 15

**Major Technical Assistance Content Areas:**
**Informal Technical Assistance[1]**

| 1990-91 | 1991-92 | 1992-93 |
|---|---|---|
| Grant Writing | Grant Writing | Grant Writing |
| Grant Administration | Grant Administration | Grant Administration |
| Child Count/Find | Child Count/Find | Child Count/Find |
| Conducting Needs Assessments | Conducting Needs Assessments | Conducting Needs Assessments |
| Providing Technical Assistance | Providing Technical Assistance | Providing Technical Assistance |
| Agency Collaboration | Agency Collaboration | Agency Collaboration |
| System Change | System Change | System Change |
| Information on Deaf-Blind Population | Information on Deaf-Blind Population | Information on Deaf-Blind Population |
| Information on Best Practices | Information on Best Practices | Information on Best Practices |
| Resource Clearinghouse | Resource Clearinghouse | Resource Clearinghouse |

[1] Conducted as a result of an informal verbal or written contact.

involvement). During the 1990-93 project years technical assistance agreements focused on 36 major content areas. A list of these major content areas and their frequencies can be found in Table 14. The most common content areas for formal technical assistance over the past three years include communication, family/parent needs, and child find/identification activities.

The TRACES Coordinators and other project staff frequently provided informal technical assistance to a variety of individuals (e.g., state project Coordinators, service delivery personnel, agency personnel, parents). Informal technical assistance is considered important yet difficult to capture in the existing evaluation measures. A recording form was developed to document informal technical assistance efforts. Table 15 illustrates the variety of informal assistance that has been offered.

Results According to the Unit of Analysis. Table 16 presents the number and percent of technical assistance activities organized by unit of analysis (e.g., individual change). Over the past three years there has been a move away from activities addressing a single aspect of a system to those that address either individuals, several aspects of a system, or all aspects of a system. Addressing a single aspect of a system is usually an ineffective strategy for bringing about change.

Results According to Other Groupings. Three other categorization schemes are used to present the results for the 1991-92 and 1992-93 project years. These include: key service, administrative level, and targets for change. Tables 17, 18 and 19 present the number and percent of formal technical assistance activities by each of these three categorization schemes.

The most frequent key service that was addressed by technical assistance activities was for the provision of technical assistance (n=151). This was followed by direct service (n=83) and project management (n=58). The most frequent specific foci were "provide special education" (n=62), "identification" (n=32) and resources to professionals, paraprofessional and parents (n=31).

Table 16

**Technical Assistance Activities Organized by Unit of Analysis**

| Unit of Analysis | 1990-91 | | 1991-92 | | 1992-93 | |
|---|---|---|---|---|---|---|
| | Frequency | Percent | Frequency | Percent | Frequency | Percent |
| Individual Change | 8 | 8.9 | 6 | 7.8 | 13 | 14.0 |
| System Component Change | 51 | 56.7 | 6 | 7.8 | 4 | 4.3 |
| System Components Change | .20 | 22.2 | 43 | 55.8 | 51 | 54.8 |
| System Change | 11 | 12.2 | 22 | 28.6 | 25 | 26.9 |

## Table 17

## 307.11 Key Services Addressed: Formal Technical Assistance[1]

| Key Services | 1990-91 | 1991-92 | 1992-93 |
|---|---|---|---|
| **Grant Administration** | | | |
| Grant Administration | | 8 | 13 |
| Collaboration/Ongoing Coordination | | 1 | 3 |
| Grant Development | N\A | 14 | 0 |
| Child Count/Census | | 4 | 13 |
| Dissemination | | 0 | 2 |
| **Total** | | 27 | 31 |
| **Direct Service** | | | |
| Identification | | 8 | 24 |
| Programs | | 11 | 8 |
| Services to Families | N/A | 9 | 15 |
| Coordinated Plans | | 2 | 3 |
| Evaluation of Effectiveness | | 2 | 1 |
| **Total** | | 32 | 51 |
| **Technical Assistance** | | | |
| Provide Special Education | | 25 | 37 |
| Inservice and Preservice Training | | 7 | 2 |
| Replication | | 4 | 1 |
| Parental Involvement | N/A | 7 | 13 |
| Resources to Professionals, Paraprofessionals and Parents | | 16 | 15 |
| Integration | | 6 | 6 |
| Pre-Service Education | | 0 | 1 |
| Transition | | 0 | 9 |
| Evaluation of Effectiveness | | 2 | 0 |
| **Total** | | 67 | 84 |

[1] Technical assistance activities often addressed more than one key service. As a result, N's do not correspond to the total number of technical assistance agreements.

## Table 18

### Administrative Levels Addressed Through Technical Assistance: Formal Technical Assistance

| Administrative Levels | 1990-91 | | 1991-92 | | 1992-93 | |
|---|---|---|---|---|---|---|
| | Cases | Percent | Cases | Percent | Cases | Percent |
| State/Multi-state | | | 51 | 66.2 | 47 | 50.5 |
| Region with state | | | 1 | 1.3 | 0 | |
| Local | | | 15 | 19.5 | 32 | 34.4 |
| Building | N/A | | 6 | 7.8 | 0 | |
| Classroom | | | 0 | | 3 | 3.2 |
| Family | | | 4 | 5.2 | 11 | 11.8 |
| Individual | | | 0 | | 0 | |
| **Total** | | | 77 | 100.00 | 93 | 100.0 |

Table 19

**Targets for Change Addressed Through Technical Assistance: Formal Technical Assistance[1]**

| Targets for Change | 1990-91 (N) | 1991-92 (N) | 1992-93 (N) |
|---|---|---|---|
| Vision/Philosophy | N/A | 5 | 5 |
| Policies/Rules | | 3 | 5 |
| Services/Programs | | 26 | 52 |
| Resources | | 10 | 40 |
| Administration/Management | | 6 | 4 |
| Effective Practices | | 38 | 53 |
| Personnel | | 32 | 7 |
| Collaborative Relationships | | 7 | 7 |
| Clients/Constituents | | 10 | 3 |
| Evaluation | | 3 | 5 |
| All | | 22 | 24 |
| **Total** | | 162 | 205 |

[1] Technical assistance activities often addressed more than one target for change. As a result, N's do not correspond to the total number of technical assistance agreements.

The most frequent administrative level addressed through technical assistance activities was the state/multi-state level (n=96). This was followed by the local level (n=78).

The most frequent targets for change addressed through technical assistance activities were "effective practices" (n=91), "services/programs" (n=78), and "resources" (n=50). Forty six technical assistance activities focused on all possible targets for change.

**Evaluation Level Results: Technical Assistance Effectiveness**

The data that pertain to the impact of technical assistance will be presented for each level of evaluation.

Level I: Satisfaction. Consumer satisfaction was evaluated using several dependent measures. The McCallon Scale was used to measure the extent to which technical assistance recipients were satisfied with workshops or inservice sessions. The extent of satisfaction was measured by a seven point scale that was used to rate seven items pertaining to the organization, delivery, and content of the group session.

The mean ratings of the McCallon Scale items and the overall scale can be found in Table 20. Overall the result indicate a consistent and high degree of consumer satisfaction for the workshops or inservice sessions as measured by the McCallon items. Based on a scale from one to seven the overall mean ratings across McCallon items ranged from 6.21 to 6.27 across the three years.

The Technical Assistance Evaluation Form was designed to measure satisfaction with the overall technical assistance effort. One or more individuals, who were involved with the technical assistance agreement from its conception to the final activity, complete the form. There are six items on the form and they are rated using a five point scale that rates each item according to the degree of agreement with the item (i.e., strongly disagree to strongly agree). Table 21 shows the mean ratings for the items that pertain to the overall technical assistance

Table 20

## Mean Ratings of McCallon Scale Items

| Items | 1990-91<br>N = 33 Cases<br>Mean | 1991-92<br>N = 22 Cases<br>Mean | 1992-93<br>N = 11 Cases<br>Mean |
|---|---|---|---|
| 1. The organization of the workshop was . . . | 6.11 | 6.28 | 6.28 |
| 2. The objectives of the workshop were. . . | 6.11 | 6.17 | 6.17 |
| 3. The work of the presenter(s) was . . . | 6.31 | 6.37 | 6.37 |
| 4. The ideas and activities of the workshop were. . . | 6.27 | 6.25 | 6.25 |
| 5. The scope (coverage) was . . . | 6.06 | 6.07 | 6.07 |
| 6. My attendance at this workshop should prove . . . | 6.28 | 6.14 | 6.14 |
| 7. Overall, I consider this workshop . . . | 6.23 | 6.27 | 6.27 |
| Overall | **6.27** | **6.22** | **6.21** |

## Table 21

## Mean Rating of the Technical Assistance Satisfaction Form

| Items | 1990-91<br>N = 62 Cases<br>Mean | 1991-92<br>N = 43 Cases<br>Mean | 1992-93<br>N = 38 Cases<br>Mean |
|---|---|---|---|
| 1. The TA objective was met and the outcome achieved | 4.67 | 4.61 | 4.66 |
| 2. The TA provider was prepared to deliver the TA | 4.82 | 4.76 | 4.79 |
| 3. The TA provider possessed the necessary expertise to deliver the TA | 4.80 | 4.83 | 4.79 |
| 4. The TA provider kept the focus of the TA on the intended objective | 4.69 | 4.66 | 4.66 |
| 5. The TA was delivered at a desirable time during the project year | 4.52 | 4.50 | 4.74 |
| 6. Overall project staff were well satisfied with the TA provided | 4.68 | 4.71 | 4.82 |
| Overall | **4.69** | **4.68** | **4.74** |

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Table 22

**Mean Ratings of Meeting Satisfaction From Items**

| Items | 1990-91 N = 19 Cases Mean | 1991-92 N = 14 Cases Mean | 1992-93 N = 7 Cases Mean |
|---|---|---|---|
| 1. The pre-meeting information was accurate and helpful. | 3.89 | 4.48 | 4.44 |
| 2. The meeting met its advertised objectives. | 4.28 | 4.82 | 4.48 |
| 3. The content of the meeting was useful. | 4.52 | 4.82 | 4.52 |
| 4. The meeting was well planned. | 4.48 | 4.65 | 4.50 |
| 5. The accommodations were excellent. | 4.04 | 4.56 | 4.47 |
| Overall | **4.26** | **4.68** | **4.48** |

Table 23

**Mean Ratings of the Impact Evaluation**
**Staff Self Report**

| Items | 1990-91<br>N = 16 Cases<br>Mean | 1991-92<br>N = 9 Cases<br>Mean | 1992-93<br>N = 3 Cases<br>Mean |
|---|---|---|---|
| 1. At this time, I think the workshop or consultation provided me with useful information. | 4.53 | 4.61 | 4.57 |
| 2. At this time, I believe that the format of the workshop or consultation was useful in providing practical information. | 4.46 | 4.35 | 4.64 |
| 3. I was able to implement strategies that were discussed during the workshop or consultation. | 3.94 | 4.24 | 4.21 |
| 4. Positive changes have been noted in students due to the information that I was able to implement from the workshop or consultation. | 3.26 | 3.98 | 3.92 |
| Overall | **3.99** | **4.29** | **4.35** |

## Table 24

### Mean Ratings of the Consultant Evaluation Form

| Items | 1990-91 N/A Mean | 1991-92 N = 7 Cases Mean | 1992-93 N = 2 Cases Mean |
|---|---|---|---|
| 1. The consultant was knowledgeable in the area in which technical assistance was provided. | | 4.76 | 4.25 |
| 2. The consultant was flexible and able to address my concerns. | | 4.59 | 3.33 |
| 3. The consultant was able to explain and model appropriate practices and procedures effectively. | | 4.77 | 4.25 |
| 4. The consultant was able to identify additional resources that might be helpful. | | 4.75 | 3.67 |
| 5. The consultant was able to work effectively within the structure of this site to promote his/her ideas. | | 4.78 | 4.00 |
| 6. The purposes and objectives of the consultation were made clear. | | 4.74 | 4.00 |
| 7. The consultant met all of his/her obligations, as I understood them. | | 4.87 | 3.67 |
| 8. The consultant was punctual, dependable and honored time/scheduling commitments. | | 4.83 | 3.75 |
| 9. Overall, this consultant was very effective in helping me implement agreed upon changes. | | 4.67 | 4.25 |
| Overall | | **4.75** | **3.94** |

## Table 25

## Percent Correct, Pre-posttest Results

| | 1990-91<br>N = 23 Cases | 1991-92<br>N = 16 Cases | 1992-93<br>N = 4 Cases |
|---|---|---|---|
| Pre-Test | | | |
| Mean % Correct | 41.96 | 44.48 | 34.97 |
| S.D. | 20.68 | 31.6 | 24.78 |
| Post-Test | | | |
| Mean % Correct | 79.60 | 84.84 | 82.53 |
| S.D. | 11.95 | 15.3 | 12.55 |
| Difference | | | |
| Mean % Correct Difference | 37.64 | 40.36 | 47.56 |
| S.D. | 19.18 | 28.77 | 25.67 |

process. Based on responses from individuals using a five point rating scale, the range in satisfaction with the overall technical assistance process from 4.68 to 4.74.

The Meeting Satisfaction Form was used for technical assistance via meetings. Meeting participants rated the organization and content of meetings using a five point scale ranging from strongly disagree (i.e., one point) to strongly agree (i.e., five points). The mean satisfaction ratings of the meetings are contained in Table 22. Overall, the participants rated the meetings favorably (means ranged from 4.26 to 4.68).

The Self Report Impact Evaluation Form was developed for recipients of technical assistance to indicate their perceived benefits from the technical assistance. The form also assesses the perceived benefits for students because of technical assistance. The results are presented in Table 23. Based on a five point scale, the recipients indicated positive benefits from technical assistance. The recipients also indicated that positive changes were observed in students because of their ability to implement information gained from the technical assistance. There has been a slight increase in the mean response over the three years on this measure.

The Consultant Evaluation Form was developed to capture recipient satisfaction for work accomplished by a consultant working on-site. The results are presented in Table 24. Based on a five point scale, the recipients provided a much more positive response to the work of consultants during the 1991-92 year than during the 1992-93 project year.

Level II: Skill/Knowledge Acquisition. Pre-post tests were used to measure skill/knowledge acquisition. The tests were designed by the consultants who delivered the technical assistance and the content of the tests were specific to the target content areas or topics of the technical assistance activities. Data from the various pre-post tests were combined for the analysis.

The pretest mean percent results, posttest mean percent results, and the pre-posttest mean percent difference results can be found in Table 25. The table presents the statistics for two test points. In general, the mean percentage difference for the pre-posttest results from technical

assistance activities was significant during each of the three project years.

Level III: Skill/Knowledge Implementation. A frequent measure of technical assistance has been consultant recommendations. Typically consultants make recommendations to the technical assistance recipients while conducting on-site visitations or consultations. The recommendations are very specific to the goal and objectives of the technical assistance activity and the needs of the recipients. After the initial on-site visit the consultant usually checks progress towards implementing the recommendations on subsequent visits.

The consultant recommendation data were aggregated and analyzed for the 1990-93 project years. Tables 26 through 31 contain the number and percent of recommendations that were implemented to various levels, and the length of time between baseline and post observations (1991-92 and 1992-93 project years only). Of the 1306 recommendations that were made to technical assistance recipients 821 or 62.9 percent were fully implemented. Of the three years, the greatest percent of recommendations were fully implemented during the 1991-92 project year (76.3%).

The most frequently made and most fully implemented recommendations were those that pertained to Direct Service Provider Practices/Procedures. Of the 513 recommendations that were made, 71.9 percent were fully implemented by the technical assistance recipients. The fewest recommendations were made in the area of classroom/school environment (n=21). The category of recommendation least fully implemented over the project period pertained to home/community environment (47.9%). Generally speaking, the longer the time between when the recommendations were made and when the final assessment of their implementation was conducted, the more fully implemented were the recommendations. This was especially the case for those recommendations related to specific children.

Level IV: Child Change. Similar to the implementation data, the child change data vary according to the technical assistance activity (e.g., behavior intervention data, communication

data). Tables 32 through 36 presents the technical assistance activities that had direct impact on children and/parents.

Table 26

**Child Centered Consultant Recommendations**

| | 1990-91 | | | 1991-92 | | | 1992-93 | | |
|---|---|---|---|---|---|---|---|---|---|
| Level of Implementation | N[1] | Percent[2] | Length[3] | N | Percent | Length | N | Percent | Length |
| Fully Implemented | 50 | 58.8 | -- | 30 | 69.8 | 4.67 | 48 | 49.5 | 5.50 |
| Partially Implemented | 19 | 22.4 | -- | 5 | 11.6 | 2.00 | 25 | 25.8 | 5.40 |
| Initiated | 9 | 10.6 | -- | 6 | 14.0 | 9.00 | 9 | 9.3 | 5.00 |
| No Progress | 7 | 8.2 | -- | 2 | 4.6 | 9.00 | 15 | 15.5 | 3.46 |
| Total | 85 | 100.0 | -- | 43 | 100.0 | 5.10 | 97 | 100.0 | 5.11 |

[1] The number of consultant recommendation made in this category that were implemented to this level.

[2] The percent of total consultant recommendations this number represents in this category.

[3] The average length of time, in months, between when the recommendation was made and the final assessment of implementation was made.

Table 27

**Service Provider Centered Consultant Recommendations**

| Level of Implementation | 1990-91 | | | 1991-92 | | | 1992-93 | | |
|---|---|---|---|---|---|---|---|---|---|
| | N[1] | Percent[2] | Length[3] | N | Percent | Length | N | Percent | Length |
| Fully Implemented | 81 | 49.2 | -- | 282 | 86.5 | 4.43 | 6 | 27.3 | 5.50 |
| Partially Implemented | 36 | 21.8 | -- | 20 | 6.1 | 3.36 | 3 | 13.6 | 5.40 |
| Initiated | 24 | 14.5 | -- | 13 | 4.0 | 4.50 | 13 | 59.1 | 5.00 |
| No Progress | 24 | 14.5 | -- | 11 | 3.4 | 3.38 | 0 | -- | -- |
| Total | 165 | 100.0 | -- | 326 | 100.0 | 4.33 | 22 | 100.0 | 3.14 |

[1] The number of consultant recommendation made in this category that were implemented to this level.

[2] The percent of total consultant recommendations this number represents in this category.

[3] The average length of time, in months, between when the recommendation was made and the final assessment of implementation was made.

Table 28

**Classroom/School Environment Centered Consultant Recommendations**

| | 1990-91 | | | 1991-92 | | | 1992-93 | | |
|---|---|---|---|---|---|---|---|---|---|
| Level of Implementation | N[1] | Percent[2] | Length[3] | N | Percent | Length | N | Percent | Length |
| Fully Implemented | 9 | 50.0 | -- | 2 | 66.7 | 5.00 | 0 | -- | -- |
| Partially Implemented | 2 | 11.1 | -- | 1 | 33.3 | 5.00 | 0 | -- | -- |
| Initiated | 3 | 16.7 | -- | 0 | -- | -- | 0 | -- | -- |
| No Progress | 4 | 22.2 | -- | 0 | -- | -- | 0 | -- | -- |
| Total | 18 | 100.0 | -- | 3 | 100.0 | 5.00 | 0 | -- | -- |

[1] The number of consultant recommendation made in this category that were implemented to this level.

[2] The percent of total consultant recommendations this number represents in this category.

[3] The average length of time, in months, between when the recommendation was made and the final assessment of implementation was made.

Table 29

**Home/Community Environment Centered Consultant Recommendations**

| | 1990-91 | | | 1991-92 | | | 1992-93 | | |
|---|---|---|---|---|---|---|---|---|---|
| Level of Implementation | N[1] | Percent[2] | Length[3] | N | Percent | Length | N | Percent | Length |
| Fully Implemented | 21 | 52.5 | -- | 2 | 33.3 | 4.50 | 0 | -- | -- |
| Partially Implemented | 7 | 17.5 | -- | 4 | 66.7 | 3.00 | 2 | 100.0 | 3.00 |
| Initiated | 7 | 17.5 | -- | 0 | -- | -- | 0 | -- | -- |
| No Progress | 5 | 12.5 | -- | 0 | -- | -- | 0 | -- | -- |
| Total | 40 | 100.0 | -- | 6 | 100.0 | 3.50 | 2 | 100.0 | 3.00 |

[1] The number of consultant recommendation made in this category that were implemented to this level.

[2] The percent of total consultant recommendations this number represents in this category.

[3] The average length of time, in months, between when the recommendation was made and the final assessment of implementation was made.

Table 30

**Policy/Administrative Centered Consultant Recommendations**

| | 1990-91 | | | 1991-92 | | | 1992-93 | | |
|---|---|---|---|---|---|---|---|---|---|
| Level of Implementation | N[1] | Percent[2] | Length[3] | N | Percent | Length | N | Percent | Length |
| Fully Implemented | 107 | 56.0 | -- | 56 | 60.2 | 3.99 | 28 | 73.6 | 6.40 |
| Partially Implemented | 43 | 22.5 | -- | 15 | 16.1 | 4.33 | 5 | 13.2 | 6.40 |
| Initiated | 24 | 12.6 | -- | 9 | 9.7 | 4.19 | 5 | 13.2 | 6.60 |
| No Progress | 17 | 8.9 | -- | 13 | 14.0 | 2.38 | 0 | -- | -- |
| Total | 191 | 100.0 | -- | 93 | 100.0 | 3.84 | 38 | 100.0 | 6.45 |

[1] The number of consultant recommendation made in this category that were implemented to this level.

[2] The percent of total consultant recommendations this number represents in this category.

[3] The average length of time, in months, between when the recommendation was made and the final assessment of implementation was made.

Table 31

**Collaboration/Dissemination Centered Consultant Recommendations**

| | 1990-91 | | | 1991-92 | | | 1992-93 | | |
|---|---|---|---|---|---|---|---|---|---|
| Level of Implementation | N[1] | Percent[2] | Length[3] | N | Percent | Length | N | Percent | Length |
| Fully Implemented | 41 | 45.1 | -- | 26 | 51.0 | 3.81 | 32 | 91.3 | 4.20 |
| Partially Implemented | 23 | 25.3 | -- | 14 | 27.5 | 3.45 | 1 | 2.9 | 9.00 |
| Initiated | 16 | 12.0 | -- | 6 | 11.8 | 4.75 | 1 | 2.9 | 7.00 |
| No Progress | 11 | 12.0 | -- | 5 | 9.7 | 2.25 | 1 | 2.9 | 3.00 |
| Total | 91 | 100.0 | -- | 51 | 100.0 | 3.67 | 35 | 100.0 | 4.40 |

[1] The number of consultant recommendation made in this category that were implemented to this level.

[2] The percent of total consultant recommendations this number represents in this category.

[3] The average length of time, in months, between when the recommendation was made and the final assessment of implementation was made.

Table 32

**Description of Technical Assistance Activities Directly Impacting Children and Parents: Northeast Region**

| State | TAA # (Year) | Content | Target of Intervention | Target Audience | Impact Data on Families | Impact Data on Children |
|---|---|---|---|---|---|---|
| DE | NE-710-DE | Effective practices for inclusion | Local-Child | LEA personnel | Families are now receiving support. | Initially, the 2 students in the nursing home were not receiving any educational services. This evolved into receiving educational services, some of which were community based. Now, one of the children is attending public school and the other will by next fall. |
| ME | NE-706-ME Summer Institute follow-up | Functional communication, O&M | Classroom-Child | Teachers | | One child is now receiving O&M training, another is now using an augmentative communication system |
| NH | NE-709-NH | Transition | Local-Child | Family members, LEA personnel, other agency personnel | | Several youth who are deaf-blind are now working in the community whereas none were working before. |
| CT | Summer Institute follow-up | Functional communication, O&M | Classroom-Child | Teachers | The parents of this child are becoming much more involved in the education of their child both at school and at home. | A communication system has been developed for one student. |
| NY | NE-702-NY | Facilitate parental involvement in the education of their children | State-Family | Parents, 307.11 personnel | A parent support group has now been established. | |
| RI | NE-607-RI | Inclusion | Local-Child | Teachers | | Children who are deaf-blind are now attending their neighborhood school. |
| MA | Summer Institute follow-up | Functional communication, O&M | Local-Child | Teachers | | A functional activity program has been developed for one child. |

Tab

## Description of Technical Assistance Activities Directly Impacting Children and Parents: South Central Region

| State | TAA # (Year) | Content | Target of Intervention | Target Audience | Impact Data on Families | Impact Data on Children |
|---|---|---|---|---|---|---|
| AR | SC-711-AR | Family support strategies | Family | Family members | Parents were helped in developing cases to present to LEA's to get needs of their children met | |
| AR | SC-710-AR | Functional Assessment & programming | District-Child | LEA personnel & Parents | Parents gained knowledge & skills in FA to use at home | Recommended strategies have been implemented for two children resulting in more effective communication |
| FL | SC-722-FL | Effective Educational Practices | Local-Child | LEA Personnel | | Four children who are deaf-blind have been identified as a result of teacher input and are now receiving more appropriate instruction |
| KY | SC-630-KY Continuation | Consumer support network | Family-Child | Family members - consumers | AADB Chapter formed | AADB Chapter formed |
| MS | SC-750-MS | School to work transition | Local-Child | Families, service providers | | One student now has job, another has communication system & more opportunities for integration w/natural supports |
| TN | SC-770-TN | Identification | State | 307.11 personnel | | Child count went up from 32 to 103. Those identified can now receive more appropriate instruction |

Table [illegible]

**Description of Technical Assistance Activities**
**Directly Impacting Children and Parents: Southeast Region**

| State | TAA # (Year) | Content | Target of Intervention | Target Audience | Impact Data on Families | Impact Data on Children |
|---|---|---|---|---|---|---|
| GA | SE-770-GA | Continued development of CBI demonstration site | Local-Child | Educational Personnel | | Four students are participating more fully in their communities. Also, all elementary student receiving Sp. Ed. services will be educated in community schools rather than the central segregated school starting next year. |
| MD | SE-730-MD | Parental involvement in education of their children | Family-Child | Families | There is more involvement of parents within schools, especially in the area of developing quality of life activities | |
| SC | SE-760-SC | Regionalize Service delivery system | State-Region | Administrators | | One region was funded to develop early childhood centers that would include at least one child who is deaf-blind. |

C7

C8

Table 35

## Description of Technical Assistance Activities Directly Impacting Children and Parents: North Central Region

| State | TAA # (Year) | Content | Target of Intervention | Target Audience | Impact Data on Families | Impact Data on Children |
|---|---|---|---|---|---|---|
| IA | NC-611-IA | Continued assistance in development of parent group | Family-Child | Families | Parents trained in conducting needs assessment interviews. | |
| SD | NC-604-SD<br>NC-710-SD | Video-tape refinement and impact evaluation | Family-Child | Families | The results of the study indicate that the videotape "Helping Your Child Learn" were useful to parents | |

Tab

## Description of Technical Assistance Activities Directly Impacting Children and Parents: Western Region

| State | TAA # (Year) | Content | Target of Intervention | Target Audience | Impact Data on Families | Impact Data on Children |
|---|---|---|---|---|---|---|
| AZ | Informal | Parent Weekend | Family-Child | Families | 15 parents have gained strategies for improving family interactions, knowledge of resources and how to access them, as well as a network being established which has resulted in better advocacy with schools | |
| AZ | WR-610-AZ | Transdisciplinary assessment & programming | Local-Child | Transdisciplinary Team members | | Two children in public schools have been identified and are now being offered appropriate services |
| CA | WR-610-CA<br>WR-715-CA<br>WR-716-CA | Information, training & services for families | Family-Child | Families | 20 - 25 parents are now in a support network and have found it to be very beneficial | Two families were assisted in helping their children to own their own homes. |

C1

C2

Table 36 Continued

## Description of Technical Assistance Activities Directly Impacting Children and Parents: Western Region

| State | TAA # (Year) | Content | Target of Intervention | Target Audience | Impact Data on Families | Impact Data on Children |
|---|---|---|---|---|---|---|
| CO | WR-722-CO | Develop in-state expertise in Deaf-Blindness | State | Teachers | | 1) Hand-over-hand interpreting for one students; 2) After using all forms of communication, one student has shown decrease in tantrums and increase intent to communicate. |
| HI | WR-615-HI | Development of in-state expertise and TA delivery system | State-Child | Teachers | | In one district, all children who are deaf-blind have been included in regular classrooms |
| ID | WR-606-ID | Integration/Inclusion | School-Child | LEA personnel, parents | | In one district, three children who are deaf-blind have been included in regular classrooms |
| ID | WR-736-ID | Functional Screening | State-Child | 307.11 Personnel | | Fourteen children have validated using screening process. Two of these children were found to have some vision and assigned to appropriate programs. One child who was previously educated by himself is now being educated with other children with disabilities and is also being partially integrated. |
| ID | WR-607-ID<br>WR-737-ID | Transdisciplinary Assessment & program development | State-Child | Transdisciplinary team members | | One student has been assessed & programs developed |
| MT | WR-743-MT | Functional Screening | State-Child | 307.11 personnel | | One child has been identified who has vision in one quarter and is now able to use computer. Another child has been identified in early intervention who has an area of vision. |
| NM | WR-760-NM | Develop parent-educator teams | Local-Child | Parents, educators | | Ten children were involved, of which all had improvements in their IEPs. Three children are now participating in regular education. |

Table 36 Continued

**Description of Technical Assistance Activities Directly Impacting Children and Parents: Western Region**

| State | TAA # (Year) | Content | Target of Intervention | Target Audience | Impact Data on Families | Impact Data on Children |
|---|---|---|---|---|---|---|
| NV | WR-751-NV | Functional Screening | State-Child | 307.11 Personnel | | One student got glasses who was previously thought to be un-testable. |
| OR | WR-614-OR | Program development & communication, interpreting services for student with Usher's | Classroom-Child | Teachers, Child | | Student w/Usher's has individualized interpreting & better access to education programs |
| OR | WR-764-OR | Develop & implement inclusive education model | School-Child | Teachers, Children | | One child who is deaf-blind included in regular classroom at OSD & participates to a greater extent w/non- disabled peers. |
| UT | WR-621-UT | Early intervention & Futures planning | Local-Families | Parents, Local service providers | Futures plans developed, Parent network strengthened | One twelve year old child now has a social network developed. |
| WY | WR-794-WY | Transdisciplinary Assessment & program development | State | Transdisciplinary Team Members | | 11 children who are deaf-blind have been identified who were not identified before |

**Objective 3: To develop a consultant pool of experts to plan and deliver technical assistance to address training/program needs.**

One of the roles of a TRACES Regional Coordinator has been to locate and contract with consultants who can assist with meeting identified technical assistance needs. Matching the appropriate consultant to the right need and recipients of service has been a major part of the process when designing and developing technical assistance requests and/or agreements. This task was supported through the creation and management of a consultant pool known as the Consultant Resource Bank.

Project consultants were identified using information collected with the TRACES Consultant Demographic Form displayed in Appendix B. TRACES Regional Coordinators distributed the forms to individuals who had served as successful consultants for the project and/or individuals referred through other resources in the field. In addition, State Coordinators of 307.11 projects and direct service providers were encouraged to nominate potential consultants.

Utilizing the Consultant Demographic Form, the potential consultants identified their major area(s) of content expertise, the student age level(s) at which their experience had been applied, and contact information. Based on the completed forms, vitae, and previous experience and contact, TRACES Coordinators selected qualified individuals to be included in the Consultant Resource Bank.

The Consultant Resource Bank was managed through a computer system. The computer system contained a record for each consultant identified which included the information gathered on the completed demographic form. Pertinent information about the consultant's technical assistance activities was also available. As technical assistance needs were identified, this

information was accessed to identify a list of appropriate consultants from which a selection could be made.

**Evaluation**

Two major approaches are used to measure the effectiveness of consultants.

1. The first approach to monitoring consultant services is through the consumer satisfaction forms completed by project personnel receiving the service. These forms indicate whether the consultant has provided the agreed upon service(s), whether they were delivered in a timely manner and if the consumers are satisfied with what they received.

2. The second approach to monitoring consultants is through the effects achieved with the service providers to whom they are consulting. Each consultant is required to take measures of impact relative to the goals and objectives of the consultation. This may include measures of skill/knowledge acquisition, recommendations implementation, and program/child change where appropriate.

**Outcome/Results**

The development and maintenance of a comprehensive and easily accessible file of well trained consultants was available across the nation throughout the project period. Updated consultant information was obtained on a regular basis. Through the use of a published guide of the Consultant Resource Bank and/or a direct computer assisted search for desired qualifications, consultants with needed expertise were identified. The state Coordinator of 307.11 services and the TRACES Coordinator reviewed the list of potential consultants and select the most appropriate individual to meet the identified technical assistance need.

The identification and recruitment of new consultants which added to the TRACES Consultant Resource Bank of experts was also ongoing. Through professional contacts and active solicitation by project staff, new expertise was identified in every region. Information updates on these new consultants were entered into the computer file as they were provided by the consultants and program staff.

A total of 240 individuals were included in the Consultant Resource Bank. These individuals have expertise in a variety of content areas and with a variety of consumer populations. A sample record from the published Consultant Resource File is included in. Appendix C.

Software was developed early in the third year of the project that provided interactive computer searches of files. The overall access to this computer system, however, did not occurred with the frequency anticipated. By in large this was due to the location of the system at the TRACES Central Office and the need to retrieve information from the field by telephone, mail or FAX.

In October, 1992 discussion was initiated with the newly funded National Information Clearinghouse on Children who are Deaf-Blind (DB-LINK), relative to integrating the Consultant Resource Bank with their database of consultants. It was determined this collaboration would not only provide access to a more comprehensive pool of expertise, but also provide a mechanism for easier access through national DB-LINK consortium communication system established. As a result, DB-LINK information staff took over total management of the Consultant Resource Bank. This transition was completed by the end of the final year of the TRACES project award.

**Objective 4: To select quality project reports, research findings, peer reviewed journal articles, and other materials pertaining to the provision of services to children with deaf-blindness, and to disseminate this information to the field in response to requests from state educational agencies.**

**Activities for Objective 4**

The TRACES Project developed a comprehensive dissemination plan for making practical information readily available to administrators, service providers, and parents. Dissemination content includes, but is not limited to, research findings, recent publications, effective practice reports, curricular approaches, consultant specialty area referrals, and child count methods and procedures. Information was made available in a timely manner through various means including newsletters, responses to requests from the field, peer-reviewed journal articles, book chapters/monographs, forums, presentations, consultations, electronic information services, and cooperative agreements with similarly focused organizations and agencies. Listed below is the original evaluation methods as written in the original proposal, and the outcomes/results of completed activities that supported this objective.

**Evaluation (From original proposal)**

1. Four issues of the TRACES Newsletter will be produced and distributed annually.

2. The effective practices reporting and dissemination format will be continually evaluated using the input from individuals who represent the effective practice (e.g., program site). Additionally, the professional literature will be closely monitored to ensure that effective practices dissemination procedures remain current in relation to contemporary developments in the field. Particular attention will be given to materials related to the education of children with other severe handicaps that have relevance to the education of children with deaf-blindness.

3. Concurrent sessions will be held around the topic of effective practices at the annual Project Director's Meeting. The information provided to the Project Directors was designed to guide modifications and innovations in effective practices reporting, dissemination, and replication.

4. Two presentations on topics related to the TRACES Project will be made annually at professional conference.

5. Two journal articles will be prepared each year and submitted for publication.

6. Data will be kept on the number of products disseminated through mailing lists, advertisements, flier mailings, booths at conferences, and listings in the publications of appropriate organizations. The data are monitored to ensure the efficacy of the materials dissemination effort.

7. Child count data are disseminated annually.

**Outcome/Results**

1. TRACES Newsletter

The TRACES Newsletter (previously known as TA Talks) published its first issue in the Winter of 1990-91. Published were four issues of volume 1, a special 1991 issue on effective and emerging practices, three issue of volume 2, and one issue of volume 3 in 1993. (With the approval of the project officer, the publication changed to a journal-like newsletter Deaf-Blind Perspectives, and began with volume 1, issue 1 in the fall of 1993.) The publication was distributed without cost and all interested parties were encouraged to subscribe. The TRACES Newsletter had a mailing list of approximately 3600 professionals, family members, and unaffiliated individuals with an interest, and higher education programs. The column, "Family Matters", written by past National Parent Network president Joyce Ford, was in the last two issues (Ms. Ford is now a regular contributor to Deaf-Blind Perspectives.) This column is the culmination of an effort by TRACES to be more responsive to this important constituency. Because there is no journal in the field of deaf-blindness, the TRACES Newsletter and subsequently Deaf-Blind Perspectives, have served as THE publication in the field.

2. DESIS System

As a satellite of the DESIS system, the TRACES Project was integrally involved with the DESIS system through this award period. The following TRACES activities occurred with regard to DESIS:

* Periodic updates were made to the DESIS system on our computer system when provided by OSEP.

* Abstracts of projects were taken annually from the DESIS system and disseminated annually by TRACES at the Project Directors meetings in D.C.

* DESIS was used to develop mailing lists for:
  TRACES Newsletter
  Distribution of Project Director meeting proceedings
  TRACES Project materials dissemination announcements

* Staff at Teaching Research Division utilized DESIS to reference abstracts of federal projects

* Returned TRACES Newsletter were checked against DESIS database for corrections

3. Dissemination on Information Related to Emerging and Effective Practices

Information on Effective Practices was presented at (a) the Project Directors' Meetings, (b) in the TRACES Newsletter, (c) on the Deaf-Blind Bulletin Board of SpecialNet, and (d) on an ad hoc basis through responses to inquiries received by TRACES staff in person, through the mail, and by phone. New project information (for example, projects newly funded by the Severe Disabilities Branch) was presented in abstract form in each participant's notebook at the annual Project Directors' Meeting. The Special Issue of the TRACES Newsletter (1991) was devoted to effective and emerging practices in serving children and youth with deaf-blindness. Twenty-two projects focussing on issues pertinent to children and youth who are deaf-blind were highlighted in this issue. SpecialNet, an electronic special education information service, was

used as a dissemination vehicle to share information on emerging practices to a wider audience. Finally, throughout the award period TRACES staff fielded inquiries on both a formal and informal basis as they executed the tasks associated with their positions. No formal or informal data is available to document the hundreds of inquiries asked of TRACES staff over the award period. Staff assisted inquirers with regard to information they requested on emerging and effective practices--specifically, practices that answered a question regarding a specific child's program. Staff willingly shared their expertise, and if they were unable to answer the question on site, sought out and delivered the appropriate information to the inquirer.

4. Dissemination of Child Count Data

Child count data was annually presented to attenders at the Annual Project Director's meeting and at the National Symposium on Children and Youth with Deaf-Blindness. Proceedings from the latter have been widely disseminated. Annual child count reports have been made to the federal government on an annual basis.

5. Distribution of TRACES Materials

TRACES produced original publications during this award period. These have been turned over to Teaching Research Publications for dissemination. Items produced during the 1990-93 award period are:

**Grant Writing Services for Children with Deaf-Blindness Program**
This monograph was written specifically for the 307.11 programs. (Services for Children with Deaf-Blindness Program, 34 CFR 307.11). It provides an update of the requirements and selection criteria for grants under the program. Considerations and examples of strategies to employ when writing a proposal under this program are also provided.

**Etiologies and Characteristics of Deaf-Blindness**
This monograph provides 307.11 programs, administrators, educators, parents and other care providers a better understanding of the terminology and major causes of deaf-blindness. Section I includes basic information relating to definitions, anatomy, and common disorders. Section II

provides information on specific conditions and syndromes which may result in visual and auditory impairments. Chapters in Section II are set up to closely resemble categories used in state census taking.

**Parent Training Modules**

The materials contained in this volume are designed for personnel who train parents of children and youth with dual sensory impairments to be knowledgeable consumers of intervention strategies and educational services for their children.

**Service Provider Training Modules**

The materials contained in this volume are designed for personnel who train service providers of children and youth with dual sensory impairments. These modules are designed for use in either preservice or inservice personnel preparation activities to enhance the delivery of effective educational services to children and youth with dual sensory impairments.

**One Step at a Time: A Manual for Families of Children with Hearing and Vision Impairments**

This book shares tried and true practices from families of children who are deaf-blind. Although it was written primarily for parents, this manual is of use to teachers, therapists, and other professionals involved with young deaf-blind children.

6. Journal Articles

Project staff published the following articles during this award period:

Bailey-Ayers, E., & Fredericks, H.D. (1991). An alternative approach to staff development. Journal of Visual Impairments and Blindness, 85, 302-305.

Briggs, A., Logan, K., & Alberto, P. (In press). Achieving educational change through technical assistance. Journal of Visual Impairment & Blindness.

Schalock, M.D, Fredericks, B., Dalke, B.A., & Alberto, P.A. (1994). The house that TRACES built: A conceptual model of service delivery systems and implications for change. The Journal of Special Education, 28, 203-223.

7. National Deaf-Blind Bulletin Board - SpecialNet

In conjunction with California Deaf-Blind Services, the TRACES Project developed the National Deaf-Blind Bulletin Board on SpecialNet. The board is used to electronically

disseminate any and all information that could be used by the field. Types of postings include: questions regarding an individual student, fact sheets, federal timelines for the submission of proposals, outcomes and products from funded projects, etc.

8. Contributor to The National Information Clearinghouse On Children Who Are Deaf-Blind (DB-LINK).

On Oct 1, 1992 DB-LINK was funded to become a national clearinghouse for the organization and dissemination of information regarding children who are deaf-blind. TRACES is part of this consortium effort. Specifically, TRACES contributed their consultant database to DB-LINK as well as a number of publications owned by the TRACES staff. TRACES and DB-LINK, both operated under the Teaching Research Division of Western Oregon State College, work closely together and two staff members share FTE across the two projects.

**Objective 5: To develop a series of monographs that address topical issues of concern and administrative functions in the field of service delivery for children with deaf-blindness.**

During the project period, project staff spent a significant portion of their time in two areas: (a) assisting coordinators of state and multi-state 307.11 projects and state/local contact people to organize personnel preparation activities, on-site consultation, or other methods for delivering technical assistance, and; (b) facilitating the development of applications by 307.11 grantees that meet the guidelines in 34 CFR Part 307 (e.g., on-going coordination with the SEA, the State's lead-agency under Part H of the IDEA, and other state agencies). To assist and enhance these project activities, TRACES staff proposed to develop a series of monographs to facilitate increased local capacity in areas of technical assistance content, interagency and intra-agency collaboration, and the processes of carrying out technical assistance (i.e., system change activities).

The monographs listed below were originally scheduled to be developed and were designed to provide the state and multi-state services coordinators with content and operational procedures to assist them to more effectively plan, develop, conduct, and evaluate system change activities.

**Monograph Titles**

Topical Monographs

1. Disabilities and Syndromes

Administrative Functions Monographs

1. Child Find & Identification
2. Needs Assessment
3. Grant Writing
4. Agency Collaboration
5. Providing Technical Assistance

The length and format of the monographs was to be determined by the particular monograph.

**Evaluation**

1. The content validity of the monographs will be evaluated by experts judging the scope of coverage, and appropriateness and accuracy of the content.

2. The usefulness and effectiveness of the monographs will be evaluated by consumers. A survey will be sent to consumers to solicit information about how the monographs were used, whether the format was useful, and the perceived effectiveness of their use.

**Outcome/Results**

During a review of Project activities at the Project Meeting held in August, 1992, it was determined that all but two monographs, Grant Writing, Services for Children with Deaf-Blindness Program and Disabilities and Syndromes were beyond the scope of the intended monographs. It was also determined that other relevant materials are available in the field covering these topics.

The monograph, Grant Writing, Services for Children with Deaf-Blindness Program, was published in November 1991 and disseminated to all 49 State and Multi-State Services to Children with Deaf-Blindness programs (see Appendix D). The publication contains step by step instructions describing how to develop and prepare an application for funding. Prior to publication the monograph was reviewed for content by a panel of senior staff members experienced in grant writing and by the project's Federal Project Officer. The monograph was used extensively by state and multi-state program personnel in the development and submission of grant applications for 34 CFR Part 307.11 grant awards for the 1992-1995 award period.

The monograph focusing on disabilities and syndromes was completed in the final year of the project under the title Etiologies and Characteristics of Deaf-Blindness (see Appendix E).

This monograph is a 78 page publication addressing definitions, anatomy, common disorders and causes of deaf-blindness. Prior to publication the monograph was reviewed for content accuracy by a prominent pediatrician, an opthamologist, and an otolaryngologist. In addition, a review was conducted by a university professor with expertise in personnel preparation in the area of instruction for children who are deaf-blind. Copies of this monograph were disseminated to the 49 state and multi-state services for children who are deaf-blind programs.

**Objective 6: To provide technical assistance to the 34 CFR 307.11 grantees in their preparation and submission of data required under Paragraph (C) (2) of Section 622 of the Individuals with Disabilities Education Act.**

**Activities of Objective 6**

The Law specifically states: The Secretary shall examine the number of children with deaf-blindness (A) reported under subparagraph (c)(1)(A) and by States; (B) served by the programs under part B of this Act and subpart 2 of part B, title 1, of the Elementary and Secondary Education Act of 1965 (as modified by chapter 1 of the Education Consolidation and Improvement Act of 1981); and (c) the Deaf-Blind Registry of each State. The Secretary shall revise the count of deaf-blind children and youth to reflect the most accurate count.

In 1986 the federal government passed new regulations that required Coordinators of state and multi-state 307.11 grants to report the number of deaf-blind children in their states. The impetus for accurate reporting came about as result of a congressional subcommittee noting extreme discrepancies between the number reported by the state and multi-state Coordinators and the annual reports from the State Department of Education. In order to resolve these differences this TA Project was asked to assist the state and multi-state Coordinators with their child count efforts.

The new reporting forms and the data now being reported (after Dec 1, 1991) from state Services for Children with Deaf-Blindness projects have been programmed into the computer facilities at Teaching Research. When a Coordinator reports the child count information from the state or states for which he or she is responsible the information is entered into the computer. When the next report is due, the Coordinator will receive a computer printout of the last report and will be given an opportunity to update their reported information. In addition, TRACES has

produced a software program that can be used by states to record, store and retrieve their data. This was sent to all states that operate on IBM and Lotus spreadsheet.

**Evaluation of Objective 6**

1. Production of an annual child count report containing accurate information about the nation's deaf/blind children and youth is the main data base for evaluative judgments. An annual predictive study will be conducted to project the expected numbers of dual sensory impaired children and youth in each state. Comparison of the actual child count numbers to these expected numbers will provide data for evaluating the effectiveness of the technical assistance in this area. In addition, a major evaluation question will center on the project's ability to reconcile the difference in the counts between the State Department of Education and the state and multi-state Coordinators of 307.11 grants.

2. This evaluation plan includes an expansion and revision of the existing process that includes updating of information received from the states with at least quarterly contacts with the 307.11 grant Coordinators to further reduce discrepancies in their reports, assisting the federal government in interpretation of the results, preparing individual state summaries as requested, assisting states in planning expanded data collection efforts, and preparing at least one annual report. Recently there it has been possible to get approval on a new set of data collection forms that include additional information about each student. The new areas covered include an expanded etiology section, identification of the educational setting and a description of the living arrangements. These new data will become the baseline information for future evaluation efforts as they provide the opportunity to measure change along a whole new dimension.

**Outcome/Results**

The following is an overview of the various achievements that have occurred during the three year project period. The accuracy, completeness and ease of reporting are the major accomplishments that have been achieved. There has been a steady growth in the identification of the numbers of children with deaf/blindness. This growth is a result of several factors, not the least of which is a dramatically improved set of identification procedures in most of the states. One of the functions of the TA has been to help states improve the way they locate and identify students. Several meetings and TA efforts have been focused on developing "best

practices" and making that information available to other states. Because of the national scope of the TRACES project, states no longer have to rely on their own expertise to improve the quality of their programs. As workable and effective methods have been developed or discovered, the approaches have been shared with other states.

The accuracy of the reporting has also improved. The first efforts were aimed at locating any and all children that might qualify for Deaf/Blind services. After those numbers were stable and representative of the expected national incidence rates, a more intense effort was begun to be sure that all of the necessary diagnostic information was available on each child. Because during this time period there was additional information required on the living and schooling settings, we were able to add significantly to the demographic description of each child.

During the three years of the project a significant step in the ease of reporting was accomplished. We were able to purchase and modify a software program that could be used by the states to record and report their census data. We entered all of their data the first year and after that we sent them a disc with a format that allowed them to easily update or add new information on each student. They could then simply send us the disk and we could summarize the data on a national basis. By the end of the project nearly all of the states are using the automated system and the turnaround time for completing the national report is considerably shorter.

There are two other accomplishments that are noteworthy. The first is the fact that the national numbers have increased from 6656 in 1990 to 8405 in 1993. It is extremely important to note that this increase did not occur in isolation and is proportional to the increase in the overall number of students with all types of handicapping conditions. The ratio appears to be

holding at two students with deaf/blindness for every 1000 students served in special education programs.

The second major accomplishment has to do with the national reporting of the Deaf/Blind census data. Each year the Office of Special Education Programs publishes an "Annual Report to Congress" on all students served by special education programs. These data are presented across a variety of domains such as age, diagnostic category, type of schooling, etc. In every report up to 1993 the numbers for the category of Deaf/Blindness have been incredulously low (1400). Further analysis showed that the students with the dual sensory impairment of Deaf/Blindness are typically reported by states as "multi-disabled". There was no explanation of the larger numbers (8400) found on the mandated census by the state coordinators of Deaf/Blind programs. After several meetings and discussion of the data, it was agreed that the Deaf/Blind annual census would be included in the Annual Report to Congress and the reference to the low numbers would be footnoted to reflect the additional data source. The actual Deaf/Blind census data will be published in the appendix of that report.

**Objective 7: To provide planning assistance and managerial support for programmatically substantive annual meetings in Washington, D.C. for directors of projects serving children and with deaf-blindness.**

The purpose of the annual Project Directors' meeting is to provide the Directors and Coordinators of projects funded through the Severe Disabilities Branch, OSEP information in the following areas: a) content pertaining to service delivery effective practices, b) input on child find activities (i.e., the deaf-blind registry), c) the guidelines for proposal development used by 307.11 grantees, and d) additional topics generated by VI-C Coordinators or project staff in response to new issues, pending legislation, significant court cases, etc. The responsibility for planning, implementing, and evaluating the meeting is an opportunity to promote system change activities.

The Project Directors' meetings planned and coordinated by the TRACES Project have taken place in and around Washington, D.C. on the following dates: November 6-8, 1990; November 18-20, 1991; and, October 26-28, 1992. Participants attending the meetings include: 307.11 Coordinators or their representatives, directors of severely handicapped projects, directors of system change projects, U.S. Office of Education representatives, and TRACES Project staff. The number of participants and the number of respondents to evaluations are shown in Table 37.

The meetings have taken on different formats each of the three years with different content as well. A copy of the meeting agendas can be found in Appendix F.

**Evaluation**

1. The project directors' meetings are evaluated by the 307.11 Coordinators and other participants. The usefulness of the content and the extent to which participants feel they have gained knowledge/skills is evaluated using a questionnaire.

Table 37
Number of Participants/Respondents

| Year | Participants | Respondents |
|---|---|---|
| **1990** | 125 | 65 |
| **1991** | 150 | 42 |
| **1992** | 150 | 76 |

**Outcome/Results**

There are evaluation data from a total of 183 individuals who attended the meeting over the three year period. Overall the respondents indicated the meeting was well organized and the information was valuable. Quantitative evaluation data is contained in Table 38. Quantitative results are from a five point scale with 1 = Strongly Disagree and 5 = Strongly Agree. A summary of comments made by the individuals who evaluated the meeting are contained in Tables 39 through 41.

Table 38
Summary of Ratings, 1990-1992

| Item | 1990 | 1991 | 1992 |
|---|---|---|---|
| 1. The format used for this year's meeting should be used in the future. | 3.31 | 3.33 | 3.00 |
| 2. The directory of project abstracts should prove useful to me. | 3.32 | 3.49 | 3.62 |
| 3. There was enough time available to network with colleagues. | | | |
| 4. The meeting was well organized. | NA | 3.76 | 3.18 |
| 5. The information I received prior to the meeting was adequate. | 3.72 | 3.76 | 3.41 |
| 6. The information I received from the Federal Government was what I needed as a project director. | 3.17 | 3.24 | 3.12 |
| 7. The accommodations and meals were adequate for the meeting. | 3.11 | 3.44 | 2.94 |
| Overall Mean Response | 3.34 | 3.52 | 3.81 |

**Comments:**

Participants have responded more positively from year to year on the usefulness of the project abstracts that are included in the notebooks. It would appear that they are getting better and more useful each year.

Participants have responded more positively from year to year on the location the Project Directors' Meeting has been held. While 1992 participants liked the accommodations this year, there were a number of comments about how far out it was.

On all other items, 1992 participant's mean rating were lower than for 1991 participants. These all seem to be related to two issues: not enough small group sessions with substantive discussions, and not enough time to meet individually with Federal Project Officers.

**Table 39**
**Summary of Comments, 1990-1992:**
**Most valuable aspects of the meeting**

| Most Common Responses | Number of Responses |
|---|---|
| **Most Common Response, 1990** | |
| Opportunity for networking | 33 |
| Focus group discussions | 33 |
| Keynote speaker: Rob Horner | 11 |
| Time with Project Officer | 10 |
| **Most Common Response, 1991** | |
| Opportunity for networking | 18 |
| Information from Federal Official/time with Project Officer | 18 |
| Focus/Effective Practice/Poster Session discussions | 13 |
| Keynote speaker: Gene Edgar | 10 |
| **Most Common Response, 1992** | |
| Opportunity for networking | 39 |
| Presentation by Virginia Roach: NASBE | 25 |
| Time with and information from Federal Officials | 22 |
| Small Group Sessions | 10 |

**Comments:**

For each of the past three years, respondents have indicated that the most valuable aspect of the meeting was the opportunity to network with their colleagues.

Respondents have also indicated that discussions held in small group sessions (focus/effective practice/poster) have been very valuable.

Respondents have also indicated that time with their project officer is a valuable aspect of the meeting.

Respondents have also stated that Keynote Addresses were valuable aspects of the meeting.

**Table 40**
**Summary of Comments, 1990-1992:**
**Least valuable aspects of the meeting**

| Most Common Responses | Number of Responses |
|---|---|
| **Most Common Response, 1990** | |
| Non-productive discussions in focus sessions | 17 |
| Information from Federal Government | 10 |
| Nothing | 10 |
| **Most Common Response, 1991** | |
| Non-productive discussions in focus/effective practice sessions | 7 |
| Nothing | 7 |
| Information from Federal Government | 4 |
| **Most Common Response, 1992** | |
| Part H presentation | 11 |
| Perske Keynote | 11 |
| OSEP planning process with people from COSMOS | 11 |
| Too many large group sessions, not enough substance | 10 |

**Comments:**

Respondents have identified non-productive small group sessions as one of the least valuable aspects of the Project Directors' Meeting over the past three years. (They have also identified other of these sessions as the most valuable aspect of the meetings.)

While somewhat different in nature, respondents have identified some of the information from the Federal Government as not being valuable over the past three years. (However, time with project officers is seen as one of the most valuable aspects of these meetings.)

For the first time, in 1992, respondents indicated that there was too much time spent in large groups being "talked at."

Table 41
Summary of Comments, 1990-1992:
What could be changed to improve the meeting in the future?

| Most Common Responses | Number of Responses |
|---|---|
| **Most Common Response, 1990** | |
| More sharing of project outcomes and strategies | 9 |
| Change the location | 7 |
| Provide more content | 7 |
| Provide more pre-meeting information on the focus group sessions | 7 |
| **Most Common Response, 1991** | |
| More sessions dealing with project results and/or content | 9 |
| Change the location | 5 |
| Re-arrange the agenda to break up the large and small group sessions | 4 |
| Provide addition information on name tags | 4 |
| **Most Common Response, 1992** | |
| More small group sessions where substantive discussion/problem solving around specific issues can take place | 39 |
| Specific and guaranteed time set aside to meet with Federal Project Officers | 10 |
| Provide a participant list to enhance networking | 6 |
| Have location closer to city | 6 |
| Have handouts available for all overheads | 6 |
| Have time for projects to share their results | 5 |

**Comments:**

A clear pattern exists in several areas. First, participants would like some time set aside for projects to formally share their results. Second, participants want more substantive discussion on how to resolve issues, not about what the issue are. Third, not everyone will like the location of the meeting, no matter where it is held.

# SECTION II

# FINANCIAL RECORDS

# FINANCIAL STATUS REPORT
*(Short Form)*
*(Follow instructions on the back)*

| 1. Federal Agency and Organizational Element to Which Report is Submitted | 2. Federal Grant or Other Identifying Number Assigned By Federal Agency | OMB Approval No. | Page | of |
|---|---|---|---|---|
| U.S. Department of Education<br>Grants & Contracts Services | H025C00001-92 | 0348-0039 | 1 | 1 pages |

3. Recipient Organization (Name and complete address, including ZIP code)
Teaching Research Division, Western Oregon State College
345 N. Monmouth Avenue
Monmouth, Oregon 97361

| 4. Employer Identification Number | 5. Recipient Account Number or Identifying Number | 6. Final Report | 7. Basis |
|---|---|---|---|
| 1-936001786-A3 | 20-264-7010/7015 | XX Yes No<br>Third Year | XX Cash ☐ Accrual |

| 8. Funding/Grant Period (See instructions) From: (Month, Day, Year) | To: (Month, Day, Year) | 9. Period Covered by this Report From: (Month, Day, Year) | To: (Month, Day, Year) |
|---|---|---|---|
| 10-01-93 | 03-31-94 | 06-01-93 | 03-31-94 |

| 10. Transactions: | I Previously Reported | II This Period | III Cumulative |
|---|---|---|---|
| a. Total outlays | 552,198 | 470,491 | 1,022,689 |
| b. Recipient share of outlays | 0 | 0 | 0 |
| c. Federal share of outlays | 552,198 | 470,491 | 1,022,689 |
| d. Total unliquidated obligations | | | 0 |
| e. Recipient share of unliquidated obligations | | | 0 |
| f. Federal share of unliquidated obligations | | | 0 |
| g. Total Federal share (Sum of lines c and f) | | | 1,022,689 |
| h. Total Federal funds authorized for this funding period | | | 1,064,594* |
| i. Unobligated balance of Federal funds (Line h minus line g) | | | 41,905 |

| 11. Indirect Expense | a. Type of Rate (Place "X" in appropriate box) ☐ Provisional ☐ Predetermined ☐ Final XX Fixed | | | |
|---|---|---|---|---|
| | b. Rate 8% | c. Base 332,163 | d. Total Amount 26,574 | e. Federal Share 26,574 |

12. Remarks: Attach any explanations deemed necessary or information required by Federal sponsoring agency in compliance with governing legislation.
* Approved funding is $978,303 plus carry over of $87,518 = $1,065,821. Actual carry over available was $86,291, therefore the amount authorized has been reduced by $1,227 for a revised total of $1,064,594.

13. Certification: **I certify to the best of my knowledge and belief that this report is correct and complete and that all outlays and unliquidated obligations are for the purposes set forth in the award documents.**

| Typed or Printed Name and Title | Telephone (Area code, number and extension) |
|---|---|
| Michael B. Stewart, Business Manager | (503) 838-8402 |
| **Signature of Authorized Certifying Official** | **Date Report Submitted** |
| Michael B. Stewart | January 30, 1995 |

Previous Editions not Usable

Standard Form 269A (REV 4-88)
Prescribed by OMB Circulars A-102 and A-110



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# FINANCIAL STATUS REPORT

*(Short Form)*

*(Follow instructions on the back)*

| 1. Federal Agency and Organizational Element to Which Report is Submitted | 2. Federal Grant or Other Identifying Number Assigned By Federal Agency | OMB Approval No. | Page | of |
|---|---|---|---|---|
| U.S. Department of Education<br>Grants & Contracts Services | H025C00001-92 | 0348-0039 | 1 | 1 pages |

3. Recipient Organization (Name and complete address, including ZIP code)
Teaching Research Division, Western Oregon State College
345 N. Monmouth Avenue
Monmouth, Oregon 97361

(3 Year Summary)

| 4. Employer Identification Number | 5. Recipient Account Number or Identifying Number | 6. Final Report | 7. Basis |
|---|---|---|---|
| 1-936001786-A3 | 1169/1179; 1180/1188; 7010/7015 | XX Yes No | XX Cash ☐ Accrual |

| 8. Funding/Grant Period (See instructions) From: (Month, Day, Year) | To: (Month, Day, Year) | 9. Period Covered by this Report From: (Month, Day, Year) | To: (Month, Day, Year) |
|---|---|---|---|
| 10-01-90 | 03-31-94 | 10-01-90 | 03-31-94 |

| 10. Transactions: | I Previously Reported | II This Period | III Cumulative |
|---|---|---|---|
| a. Total outlays | | | 2,876,850 |
| b. Recipient share of outlays | | | 0 |
| c. Federal share of outlays | | | 2,876,850 |
| d. Total unliquidated obligations | | | 0 |
| e. Recipient share of unliquidated obligations | | | 0 |
| f. Federal share of unliquidated obligations | | | 0 |
| g. Total Federal share (Sum of lines c and f) | | | 2,876,850 |
| h. Total Federal funds authorized for this funding period | | | 2,918,755 |
| i. Unobligated balance of Federal funds (Line h minus line g) | | | 41,905 |

| 11. Indirect Expense | a. Type of Rate (Place "X" in appropriate box) ☐ Provisional ☐ Predetermined ☐ Final XX Fixed | | | |
|---|---|---|---|---|
| | b. Rate 8% | c. Base 1,891,166 | d. Total Amount 151,293 | e. Federal Share 151,293 |

12. Remarks: Attach any explanations deemed necessary or information required by Federal sponsoring agency in compliance with governing legislation.

13. Certification: **I certify to the best of my knowledge and belief that this report is correct and complete and that all outlays and unliquidated obligations are for the purposes set forth in the award documents.**

| Typed or Printed Name and Title | Telephone (Area code, number and extension) |
|---|---|
| Michael B. Stewart, Business Manager | (503) 838-8402 |
| **Signature of Authorized Certifying Official** | **Date Report Submitted** |
| Michael B. Stewart | January 30, 1995 |

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Prescribed by OMB Circulars A-102 and A-110

# APPENDIX A

# NEEDS ASSESSMENT

# STATE PLAN FORMS

TRACES PROJECT
STATE/MULTI-STATE NEEDS SUMMARY FORM

State/Multi-State Proj._____ Date _____

622C Coord._____TRACES Coord._____

| Need Statements in Priority Order | Grant Ref. | KS Ref. |
|---|---|---|
| | | |

10-14-92

TRACES PROJECT
STAFF TECHNICAL ASSISTANCE SUMMARY FORM

Staff_____ Activity Date(s)_____

State(s) Assisted_____

| Planned Activity(ies): |
|---|
| Anticipated Outcome(s): |
| Actual Outcomes: |

10-14-92

TRACES PROJECT

Long Range State Plan Form

State:_____ Inclusive Dates of Plan:_____

Planning Participants:_____ Plan Development/Revision Date:_____

| IMPLEMENTATION/ENHANCEMENT GOAL | ACHIEVEMENT STRATEGY | RESOURCE PROVIDER | TIMELINE |
|---|---|---|---|
| | | | |

10.14.92

# APPENDIX B

# CONSULTANT DEMOGRAPHIC FORM

TRACES PROJECT
CONSULTANT DEMOGRAPHIC FORM

Name: _____
Mailing address: _____ Daytime phone: (___) _____
_____ SS#: _____
City, State, Zip: _____

**Experience: Designate by age group, areas of expertise in which you wish to continue to serve as a consultant:**

A. Infant D. Secondary
B. Preschool E. Adult
C. Elementary F. Open

| | A | B | C | D | E | F |
|---|---|---|---|---|---|---|
| 1. Adaptive PE | | | | | | |
| 2. Administrative | | | | | | |
| 3. Assessment | | | | | | |
| 4. Behavior Management | | | | | | |
| 5. Cognitive Development | | | | | | |
| 6. Communication | | | | | | |
| 7. Community Based Instruction | | | | | | |
| 8. Deinstitutionalization | | | | | | |
| 9. Diagnosis and Evaluation | | | | | | |
| 10. Grant Writing | | | | | | |
| 11. ICS/Curriculum Development | | | | | | |
| 12. IEP Development | | | | | | |
| 13. Independent/Semi-Ind Living | | | | | | |
| 14. Integration/LRE | | | | | | |
| 15. Integrated Therapy | | | | | | |
| 16. Legal/Litigation | | | | | | |
| 17. Medical Aspects | | | | | | |
| 18. Occupational Therapy | | | | | | |
| 19. Orientation/Mobility | | | | | | |
| 20. Parents/Family/Home Programs | | | | | | |
| 21. Physical Therapy | | | | | | |
| 22. Recreation Therapy | | | | | | |
| 23. Sex Education | | | | | | |
| 24. Technology/Assistive Devices | | | | | | |
| 25. Transition | | | | | | |
| 26. Vocational Training | | | | | | |
| 27. Other | | | | | | |

**Consultation Expertise in State Level Systems. Check any that apply**

| | A | B | C | D | E | F |
|---|---|---|---|---|---|---|
| 30. Administrative Planning | | | | | | |
| 31. Development of demonstration Site | | | | | | |
| 32. Development of Service Delivery: Best Practice | | | | | | |
| 33. Policy Development | | | | | | |
| 34. State Long Range Planning | | | | | | |
| 35. State-wide Systems Change | | | | | | |

Expertise mostly with:
____ Deaf Blind
____ Hearing impaired
____ Vision impaired
____ Multi-handicapped

Disability experience:
____ High functioning
____ At risk
____ Mild
____ Moderate
____ Severe
____ Profound

Have you been a TASH/ TRACES Consultant before?

Yes ____ No ____

What years? _____

What regions? NE __
NC __
NW __
SE __
SC __
SW __

Are you enclosing a Vita? Yes___ No___

In what year was it prepared? _____

Today's Date___/___/___

ta8-84

# APPENDIX C

# SAMPLE RECORD

# FROM THE CONSULTANT RESOURCE FILE

# CONSULTANT RESOURCE BOOK

TRACES Project
Monmouth, OR 97361

## DIRECTIONS FOR USING THE CONSULTANT RESOURCE BANK

The Consultant Resource Bank is divided into two major sections to assist users in locating consultants.

### Index

The index displays a listing of each state in which consultants are located. Under each state there is a listing of areas of experience reported by the consultants residing in the state. Each consultant is then listed by a locator number which coincides with the that consultant's locator number in the body of the document.

In addition, a listing of the two digit experience codes is included so that the state listings can be scanned for individuals haveing a particular expertise.

### Body

The body of the Consultant Resource Bank contains the names of all participating consultants in alphabetical order by last name. If the user knows the name of the desired consultant, he or she can go directly to this section to locate that individual

Each time the consultant resource bank is updated, new index and body pages will be distributed. The locator numbers will change, due to addition or deletion of names.

01 Adaptive PE
02 Administration
03 Assessment
04 Behavior Management
05 Cognitive Development
06 Communication
07 Community Based Instruction
08 Deinstitutionalization
09 Diagnosis and Evaluation
10 Grant Writing
11 ICS/Curriculum Development
12 IEP Development
13 Independent/Semi-Ind Living
14 Integration/LRE
15 Integrated Therapy
16 Legal/Litigation
17 Medical Aspects
18 Occupational Therapy
19 Orientation/Mobility
20 Parents/Families/Home Programs
21 Physical Therapy
22 Recreation Therapy
23 Sex Education
24 Technology/Assistive Devices
25 Transition
26 Vocational Training

30 Administrative Planning
31 Development of Demo Site
32 Development of Service Delivery
33 Policy Development
34 State Long Range Planning
35 State-wide Systems Change

ALASKA
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06 Communication . . . . . 1006
07 Community Based Instruction . 1006
09 Diagnosis and Evaluation . . . 1006
12 IEP Development . . . . . 1006
17 Medical Aspects . . . . . 1006
19 Orientation/Mobility . . . . . 1006
20 Parents/Families/Home Programs 1006
31 Development of Demo Site . . . 1006
32 Development of Service Delivery 1006

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05 Cognitive Development . . . . 1009, 1038
06 Communication . . . . . 1009, 1038, 1103, 1166, 1213, 1226, 1257
07 Community Based Instruction . 1226
09 Diagnosis and Evaluation . . . 1038, 1257
11 ICS/Curriculum Development . . 1021, 1038
12 IEP Development . . . . . 1009, 1038
14 Integration/LRE . . . . . 1021, 1038
15 Integrated Therapy . . . . . 1038
17 Medical Aspects . . . . . 1038
20 Parents/Families/Home Programs 1021, 1205
22 Recreation Therapy . . . . . 1205
23 Sex Education . . . . . 1009
24 Technology/Assistive Devices . 1226
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33 Policy Development . . . . . 1103
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03 Assessment . . . . . 1057, 1064, 1151
05 Cognitive Development . . . . 1151
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07 Community Based Instruction . 1057, 1064, 1151
08 Deinstitutionalization . . . . 1057
10 Grant Writing . . . . . 1064
11 ICS/Curriculum Development . . 1151
12 IEP Development . . . . . 1057
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20 Parents/Families/Home Programs 1064, 1151
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32 Development of Service Delivery 1057
33 Policy Development . . . . . 1064
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03 Assessment . . . . . 1003, 1012, 1033, 1055, 1074, 1084, 1088, 1098, 1099, 1108, 1111, 1119, 1140, 1175, 1204, 1222

| | |
|---|---|
| 04 Behavior Management | 1012, 1055, 1084, 1093, 1098, 1099, 1154, 1165, 1175, 1222 |
| 05 Cognitive Development | 1033, 1055, 1088, 1093, 1099, 1204 |
| 06 Communication | 1012, 1033, 1055, 1074, 1088, 1098, 1099, 1111, 1119, 1154, 1222 |
| 07 Community Based Instruction | 1003, 1012, 1055, 1074, 1084, 1088, 1098, 1099, 1108, 1119, 1140, 1154, 1175, 1190, 1204, 1222, 1250 |
| 08 Deinstitutionalization | 1012, 1084, 1099, 1154 |
| 09 Diagnosis and Evaluation | 1012, 1033, 1088, 1099, 1204 |
| 10 Grant Writing | 1033, 1099, 1108 |
| 11 ICS/Curriculum Development | 1012, 1055, 1069, 1074, 1084, 1088, 1098, 1099, 1108, 1111, 1119, 1140, 1175, 1190, 1204 |
| 12 IEP Development | 1003, 1012, 1055, 1069, 1074, 1084, 1088, 1098, 1099, 1108, 1119, 1140, 1190, 1204, 1222 |
| 13 Independent/Semi-Ind Living | 1012, 1055, 1084, 1099, 1222 |
| 14 Integration/LRE | 1003, 1012, 1055, 1069, 1074, 1084, 1088, 1093, 1098, 1099, 1108, 1119, 1140, 1154, 1175, 1190, 1204, 1222, 1250 |
| 15 Integrated Therapy | 1012, 1055, 1084, 1088, 1099, 1222 |
| 16 Legal/Litigation | 1012 |
| 17 Medical Aspects | 1012, 1088 |
| 19 Orientation/Mobility | 1088, 1111 |
| 20 Parents/Families/Home Programs | 1023, 1033, 1055, 1084, 1099, 1108, 1154, 1222 |
| 22 Recreation Therapy | 1055, 1108, 1222 |
| 23 Sex Education | 1055 |
| 24 Technology/Assistive Devices | 1055, 1084, 1098, 1222 |
| 25 Transition | 1012, 1055, 1084, 1093, 1099, 1108, 1140, 1154, 1175, 1190, 1204, 1222, 1250 |
| 26 Vocational Training | 1055, 1084, 1099, 1108, 1111, 1140, 1175, 1190, 1204, 1222, 1250 |
| 30 Administrative Planning | 1012, 1055, 1084, 1099, 1133 |
| 31 Development of Demo Site | 1012, 1055, 1084, 1088, 1093, 1099, 1133 |
| 32 Development of Service Delivery | 1012, 1055, 1069, 1084, 1088, 1099, 1133, 1154 |
| 33 Policy Development | 1012, 1055, 1084, 1088, 1133 |
| 34 State Long Range Planning | 1012, 1055, 1084, 1133, 1012, 1055, 1084, 1133, 1154 |

COLORADO

| | |
|---|---|
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| 03 Assessment | 1087, 1194 |
| 04 Behavior Management | 1194 |
| 05 Cognitive Development | 1087, 1194 |
| 06 Communication | 1087, 1167, 1255 |
| 07 Community Based Instruction | 1087, 1254, 1255 |
| 12 IEP Development | 1087, 1254 |
| 13 Independent/Semi-Ind Living | 1167, 1254 |
| 14 Integration/LRE | 1087, 1167, 1254 |
| 15 Integrated Therapy | 1167, 1254 |
| 17 Medical Aspects | 1087 |
| 19 Orientation/Mobility | 1254 |
| 24 Technology/Assistive Devices | 1167, 1254 |
| 25 Transition | 1254, 1255 |
| 30 Administrative Planning | 1167, 1254 |
| 31 Development of Demo Site | 1167 |
| 32 Development of Service Delivery | 1167 |
| 34 State Long Range Planning | 1254 |
| 35 State-wide Systems Change | 1254 |

CONNECTICUT

| | |
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| 11 ICS/Curriculum Development | 1164 |
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26 Vocational Training . . . . . 1164, 1180
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05 Cognitive Development . . . . 1039, 1240
06 Communication . . . . . 1039, 1240
07 Community Based Instruction . 1252
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10 Grant Writing . . . . . 1039
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19 Orientation/Mobility . . . . . 1039, 1049, 1085
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21 Physical Therapy . . . . . 1085
24 Technology/Assistive Devices . 1085
26 Vocational Training . . . . . 1252
32 Development of Service Delivery 1039, 1240, 1252
33 Policy Development . . . . . 1240
34 State Long Range Planning . . 1240
35 State-wide Systems Change . . 1240

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03 Assessment . . . . . 1001, 1022, 1045, 1112, 1129, 1146, 1155
04 Behavior Management . . . . . 1001, 1022, 1045, 1112, 1129
05 Cognitive Development . . . . 1001, 1022, 1045, 1071, 1112, 1129
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03 Assessment . . . . . 1127, 1128, 1134, 1138, 1142, 1177, 1243
04 Behavior Management . . . . . 1070, 1127, 1128, 1134, 1142, 1243, 1244
05 Cognitive Development . . . . 1031, 1127, 1134, 1177
06 Communication . . . . . 1070, 1128, 1134, 1243
07 Community Based Instruction . 1070, 1142, 1172, 1177, 1243, 1244
08 Deinstitutionalization . . . . 1177
09 Diagnosis and Evaluation . . . 1243
10 Grant Writing . . . . . 1052
11 ICS/Curriculum Development . . 1031, 1070, 1134, 1138, 1172, 1177, 1243, 1244
12 IEP Development . . . . . 1031, 1070, 1128, 1134, 1138, 1142, 1177, 1243, 1244
13 Independent/Semi-Ind Living . 1031, 1243, 1244
14 Integration/LRE . . . . . 1031, 1128, 1134, 1177, 1243, 1244
15 Integrated Therapy . . . . . 1243
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19 Orientation/Mobility . . . . . 1172
20 Parents/Families/Home Programs 1031, 1134, 1142, 1243, 1244
22 Recreation Therapy . . . . . 1172
23 Sex Education . . . . . 1243
24 Technology/Assistive Devices . 1138
25 Transition . . . . . 1052, 1134, 1172, 1215, 1243, 1244
26 Vocational Training . . . . . 1172, 1215, 1243, 1244
30 Administrative Planning . . . 1052
31 Development of Demo Site . . . 1142
33 Policy Development . . . . . 1052
35 State-wide Systems Change . . 1128, 1243

VERMONT
02 Administration . . . . . 1090
03 Assessment . . . . . 1017, 1090
04 Behavior Management . . . . . 1017, 1090
05 Cognitive Development . . . . 1017
06 Communication . . . . . 1017, 1090
07 Community Based Instruction . 1017
09 Diagnosis and Evaluation . . . 1135, 1017
11 ICS/Curriculum Development . . 1090
12 IEP Development . . . . . 1090, 1135
13 Independent/Semi-Ind Living . 1017, 1090, 1135
14 Integration/LRE . . . . . 1017, 1090
15 Integrated Therapy . . . . . 1090
18 Occupational Therapy . . . . . 1135
20 Parents/Families/Home Programs 1135
24 Technology/Assistive Devices . 1090
30 Administrative Planning . . . 1090
31 Development of Demo Site . . . 1090
32 Development of Service Delivery 1017, 1090
33 Policy Development . . . . . 1090
34 State Long Range Planning . . 1090
35 State-wide Systems Change . . . 1090

WASHINGTON
01 Adaptive PE . . . . . 1234
02 Administration . . . . . 1086, 1104, 1149
03 Assessment . . . . . 1002, 1016, 1083, 1086, 1104, 1169, 1183, 1184, 1234
04 Behavior Management . . . . . 1065, 1104, 1113, 1149, 1234
05 Cognitive Development . . . . 1016, 1104, 1120, 1183, 1184
06 Communication . . . . . 1002, 1016, 1083, 1086, 1104, 1120, 1148, 1149, 1183, 1184, 1234, 1236
07 Community Based Instruction . 1086, 1113, 1120, 1234

08 Deinstitutionalization . . . . 1065, 1234
09 Diagnosis and Evaluation . . . 1002, 1120, 1183
10 Grant Writing . . . . . 1113, 1120, 1149
11 ICS/Curriculum Development . . 1086, 1104, 1113, 1148
12 IEP Development . . . . . 1002, 1016, 1104, 1113, 1120, 1149, 1234
13 Independent/Semi-Ind Living . 1002, 1086, 1113, 1120, 1234
14 Integration/LRE . . . . . 1016, 1065, 1086, 1113, 1234, 1246
15 Integrated Therapy . . . . . 1113
16 Legal/Litigation . . . . . 1063, 1083, 1113
19 Orientation/Mobility . . . . . 1086, 1234
20 Parents/Families/Home Programs 1002, 1016, 1065, 1104, 1113, 1234
22 Recreation Therapy . . . . . 1086, 1234
23 Sex Education . . . . . 1104, 1148
24 Technology/Assistive Devices . 1016, 1086, 1236
25 Transition . . . . . 1113, 1120, 1234, 1236, 1246
26 Vocational Training . . . . . 1086, 1113, 1120, 1234, 1246
30 Administrative Planning . . . 1086
31 Development of Demo Site . . . 1086, 1183
32 Development of Service Delivery 1086, 1113, 1183
33 Policy Development . . . . . 1063, 1086, 1113
34 State Long Range Planning . . 1063, 1086
35 State-wide Systems Change . . 1063, 1065, 1086, 1113

WISCONSIN
01 Adaptive PE . . . . . 1008, 1147
03 Assessment . . . . . 1008, 1026, 1097, 1114, 1147, 1212
04 Behavior Management . . . . . 1008, 1114, 1147, 1212
06 Communication . . . . . 1008, 1114
07 Community Based Instruction . 1008, 1026, 1097, 1114, 1147, 1203, 1212, 1230, 1239
08 Deinstitutionalization . . . . 1008, 1026, 1114, 1212, 1230
09 Diagnosis and Evaluation . . . 1008, 1212
11 ICS/Curriculum Development . . 1008, 1147, 1203, 1212, 1230
12 IEP Development . . . . . 1008, 1097, 1147, 1203, 1212, 1230
13 Independent/Semi-Ind Living . 1008, 1212, 1230
14 Integration/LRE . . . . . 1008, 1026, 1114, 1147, 1203, 1212, 1230, 1239
15 Integrated Therapy . . . . . 1008, 1212
16 Legal/Litigation . . . . . 1026, 1212
19 Orientation/Mobility . . . . . 1008
20 Parents/Families/Home Programs 1008, 1114, 1212, 1230
22 Recreation Therapy . . . . . 1008, 1114, 1203, 1212, 1230
24 Technology/Assistive Devices . 1008, 1114
25 Transition . . . . . 1008, 1097, 1203, 1212, 1230
26 Vocational Training . . . . . 1008, 1097, 1147, 1203, 1212, 1239
30 Administrative Planning . . . 1026, 1114
31 Development of Demo Site . . . 1026
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33 Policy Development . . . . . 1026
34 State Long Range Planning . . 1008, 1026
35 State-wide Systems Change . . 1008, 1026, 1114

WYOMING
03 Assessment . . . . . 1116
05 Cognitive Development . . . . 1116
09 Diagnosis and Evaluation . . . 1116
12 IEP Development . . . . . 1116
20 Parents/Families/Home Programs 1116

1001

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CONSULTANT BEFORE: Yes
YEAR: 1985-86
REGIONS: SE
CURRENT VITA?: Yes

**AREAS OF EXPERIENCE AND EXPERTISE:** Assessment, Behavior Management, Cognitive Development, Communication, ICS/Curriculum Development, IEP Development

**AGE EMPHASIS:** Infant, Preschool, Elementary

**EXPERTISE MOSTLY WITH:**

**DISABILITY EXPERIENCE:**

1002

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PHONE:
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CONSULTANT BEFORE: Yes
YEAR: 1988-89
REGIONS: NW,
CURRENT VITA?: Yes

**AREAS OF EXPERIENCE AND EXPERTISE:** Assessment, Communication, Diagnosis and Evaluation, IEP Development, Independent/Semi-Ind Living, Parents/Families/Home Programs

**AGE EMPHASIS:** Preschool, Elementary, Secondary, Adult

**EXPERTISE MOSTLY WITH:** Deaf-Blind, Hearing impaired

**DISABILITY EXPERIENCE:** High functioning, At risk, Mild, Moderate, Severe, Profound

1003

NAME: JACKI ANDERSON

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CONSULTANT BEFORE: Yes
YEAR: 1984-88
REGIONS: SW
CURRENT VITA?: Yes

**AREAS OF EXPERIENCE AND EXPERTISE:** Administration, Assessment, Community Based Instruction, IEP Development, Integration/LRE

**AGE EMPHASIS:** Elementary, Secondary

**EXPERTISE MOSTLY WITH:**

**DISABILITY EXPERIENCE:**

1004

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ADDRESS: 6250 S.W. BURLINGAME AVE.
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CONSULTANT BEFORE: Yes
YEAR: 1987-88,1989-90
REGIONS: NW,
CURRENT VITA?: Yes

**AREAS OF EXPERIENCE AND EXPERTISE:** Assessment, Cognitive Development, Communication, ICS/Curriculum Development, IEP Development, Integration/LRE, Integrated Therapy, Parents/Families/Home Programs

**AGE EMPHASIS:** Elementary, Secondary

**EXPERTISE MOSTLY WITH:** Deaf-Blind

**DISABILITY EXPERIENCE:**

1005

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ADDRESS: 700 ACKERMAN ROAD
SUITE 440
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PHONE: (614) 447-0844
SOC. SEC. #: 021-52-1715

CONSULTANT BEFORE: Yes
YEAR: 1990
REGIONS: SC
CURRENT VITA?: Yes

**AREAS OF EXPERIENCE AND EXPERTISE:** Communication, ICS/Curriculum Development, IEP Development, Integrated Therapy, Parents/Families/Home Programs

**AGE EMPHASIS:** Infant, Preschool, Elementary, Secondary

**EXPERTISE MOSTLY WITH:** Deaf-Blind, Multi-handicapped

**DISABILITY EXPERIENCE:** Severe, Profound

1006

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CONSULTANT BEFORE: No
YEAR:
REGIONS:
CURRENT VITA?: Yes

**AREAS OF EXPERIENCE AND EXPERTISE:** Assessment, Cognitive Development, Communication, Community Based Instruction, Diagnosis and Evaluation, IEP Development, Medical Aspects, Orientation/Mobility, Parents/Families/Home Programs, Development of Demo Site, Development of Service Delivery, GENERAL DEVELOPMENT ALL DOMAINS

**AGE EMPHASIS:** Infant, Preschool, Open

**EXPERTISE MOSTLY WITH:** Deaf-Blind, Vision impaired, Multi-handicapped

**DISABILITY EXPERIENCE:** High functioning, At risk, Mild, Moderate, Severe, Profound

1007

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CONSULTANT BEFORE:
YEAR:
REGIONS:
CURRENT VITA?: Yes

AREAS OF EXPERIENCE AND EXPERTISE:

AGE EMPHASIS:

EXPERTISE MOSTLY WITH:

DISABILITY EXPERIENCE:

1008

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CONSULTANT BEFORE: Yes
YEAR: 1896
REGIONS: NC, SE
CURRENT VITA?: Yes

AREAS OF EXPERIENCE AND EXPERTISE: Adaptive PE, Assessment, Behavior Management, Communication, Community Based Instruction, Deinstitutionalization, Diagnosis and Evaluation, ICS/Curriculum Development, IEP Development, Independent/Semi-Ind Living, Integration/LRE, Integrated Therapy, Orientation/Mobility, Parents/Families/Home Programs, Recreation Therapy, Technology/Assistive Devices, Transition, Vocational Training, Development of Service Delivery, State Long Range Planning, State-wide Systems Change

AGE EMPHASIS: Open

EXPERTISE MOSTLY WITH: Deaf-Blind, Vision impaired, Multi-handicapped

DISABILITY EXPERIENCE: High functioning, Mild, Moderate, Severe, Profound

1009

NAME: CONNIE B. BARNES

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CONSULTANT BEFORE: No
YEAR:
REGIONS:
CURRENT VITA?: No

AREAS OF EXPERIENCE AND EXPERTISE: Administration, Cognitive Development, Communication, IEP Development, Sex Education

AGE EMPHASIS: Elementary, Secondary, Adult

EXPERTISE MOSTLY WITH: Hearing impaired

DISABILITY EXPERIENCE:

1010

NAME: NANCY BATSON

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SOC. SEC. #: 587-03-2703

CONSULTANT BEFORE: Yes
YEAR:
REGIONS: SW,
CURRENT VITA?: No

AREAS OF EXPERIENCE AND EXPERTISE: Communication, IEP Development, Integration/LRE, Parents/Families/Home Programs, Transition, Administrative Planning, Development of Demo Site, Development of Service Delivery, Policy Development, State Long Range Planning, State-wide Systems Change

AGE EMPHASIS: Preschool, Elementary, Secondary

EXPERTISE MOSTLY WITH: Deaf-Blind, Multi-handicapped

DISABILITY EXPERIENCE: Mild, Moderate, Severe, Profound

1011

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CONSULTANT BEFORE: Yes
YEAR: 1986-1990
REGIONS: SW
CURRENT VITA?: Yes

**AREAS OF EXPERIENCE AND EXPERTISE:** Assessment, Behavior Management, Communication, Community Based Instruction, IEP Development, Integration/LRE, Parents/Families/Home Programs, Transition, Vocational Training, Administrative Planning, Development of Demo Site, Development of Service Delivery, State Long Range Planning, State-wide Systems Change

**AGE EMPHASIS:** Preschool, Elementary, Elementary, Adult

**EXPERTISE MOSTLY WITH:** Multi-handicapped

**DISABILITY EXPERIENCE:** Mild, Moderate, Severe, Profound

1012

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CONSULTANT BEFORE: Yes
YEAR: 1895
REGIONS: NW, SC, SW,
CURRENT VITA?: No

**AREAS OF EXPERIENCE AND EXPERTISE:** Administration, Assessment, Behavior Management, Communication, Community Based Instruction, Deinstitutionalization, Diagnosis and Evaluation, ICS/Curriculum Development, IEP Development, Independent/Semi-Ind Living, Integration/LRE, Integrated Therapy, Legal/Litigation, Medical Aspects, Transition, Administrative Planning, Development of Demo Site, Development of Service Delivery, Policy Development, State Long Range Planning, State-wide Systems Change

**AGE EMPHASIS:** Open

**EXPERTISE MOSTLY WITH:** Deaf-Blind, Multi-handicapped

**DISABILITY EXPERIENCE:** Moderate, Severe, Profound

1013

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YEAR:
REGIONS:
CURRENT VITA?: No

AREAS OF EXPERIENCE AND EXPERTISE: THERAPEUTIC POSITIONING, PROMOTION OF THERAPEUTIC LIFESTYLES

AGE EMPHASIS: Open

EXPERTISE MOSTLY WITH:

DISABILITY EXPERIENCE:

1014

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SOC. SEC. #:

CONSULTANT BEFORE:
YEAR:
REGIONS:
CURRENT VITA?: Yes

AREAS OF EXPERIENCE AND EXPERTISE:

AGE EMPHASIS:

EXPERTISE MOSTLY WITH:

DISABILITY EXPERIENCE:

1015

NAME: ROBBIE BLAHA

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PHONE:
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CONSULTANT BEFORE: Yes
YEAR:
REGIONS: SC,
CURRENT VITA?: Yes

**AREAS OF EXPERIENCE AND EXPERTISE:** Behavior Management, Cognitive Development, Communication, Community Based Instruction, ICS/Curriculum Development, IEP Development, Recreation Therapy, Development of Demo Site

**AGE EMPHASIS:** Elementary, Secondary

**EXPERTISE MOSTLY WITH:** Deaf-Blind

**DISABILITY EXPERIENCE:** Moderate, Severe, Profound

1016

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REGIONS: NW,
CURRENT VITA?: No

**AREAS OF EXPERIENCE AND EXPERTISE:** Assessment, Cognitive Development, Communication, IEP Development, Integration/LRE, Parents/Families/Home Programs, Technology/Assistive Devices

**AGE EMPHASIS:** Infant, Preschool, Elementary

**EXPERTISE MOSTLY WITH:** Deaf-Blind, Vision impaired, Multi-handicapped

**DISABILITY EXPERIENCE:** High functioning, Severe, Profound

# APPENDIX D

# GRANT WRITING SERVICES

# FOR CHILDREN WITH DEAF-BLINDNESS PROGRAM

# GRANT WRITING
# SERVICES FOR CHILDREN WITH DEAF-BLINDNESS
# PROGRAM

**34 CFR Part 307.11**

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**Teaching Research Division**

November, 1991

Traces

TEACHING RESEARCH ASSISTANCE TO CHILDREN AND
YOUTH EXPERIENCING SENSORY IMPAIRMENTS

CENTRAL OFFICE

Teaching Research Division/WOSC
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Monmouth, OR 97361

The TRACES project is funded by the U.S. Department of Education,
Office of Special Education Programs. Agreement #H025C80001-91.

## INTENDED AUDIENCE, OBJECTIVES, AND FORMAT

The **intended audience** for this monograph is potential grantees under the Services for Children with Deaf-Blindness Program, 34 CFR 307.11.

The **objectives** for the monograph are:

1. To provide an update on the authorizing statute requirements of the Services for Children with Deaf-Blindness Program (34 CFR 307.11).
2. To provide an update on specific selection criteria for grants under the Services for Children with Deaf-Blindness Program (34 CFR 307.33) for each section of an application.
3. To provide particular points to consider for each section when writing an application (taken from a workbook for reviewers, staff, 1988).
4. To provide examples and strategies for each section of an application.
5. To provide a list of references.

The **format** for the monograph is:

1. A discussion of the authorizing statute requirements;
2. Some general principles for writing applications;
3. A listing of specific selection criteria for each section of an application which includes:

   a) citations from the Federal Register,
   b) points to consider, and
   c) examples and strategies.

A list of references is provided, and the appendices contain citations from the Federal Register as well as a selection criteria overview.

## GRANTS FOR SERVICES FOR CHILDREN WITH DEAF-BLINDNESS PROGRAM

The Services for Children with Deaf-Blindness Program is currently authorized under Part C, Section 622 of the Individuals with Disabilities Education Act (IDEA) which was passed in 1990. "State and multi-State projects must provide services to infants, toddlers, children and youth with deaf-blindness and technical assistance to public and private agencies, institutions and organizations providing early intervention, early identification, education, transition, vocational, and related services to children with deaf-blindness, as described at 34 CFR 307.11. Applications for State and multi-State projects will be evaluated using criteria at 34 CFR 307.33." (Federal Register, 1991, p. 51770).

**SPECIFIC AUTHORIZING STATUTE REQUIREMENTS** - 34 CFR Part 307.11

**DIRECT SERVICES** in the form of special education, early intervention, and related services as well as vocational and transitional services, should be available to children with deaf-blindness for whom a state is not obligated to provide these services under Part B of the IDEA or some other authority. These services may include: 1) identification including both diagnosis and educational evaluation; 2) programs for adjustment, education, and orientation for children with deaf-blindness; 3) services to families including consultation, counseling, and training; and 4) preparation of a coordinated plan for each child served.

**TECHNICAL ASSISTANCE** can be provided to public and private agencies, institutions, and organizations which are providing early intervention, educational, transitional, vocational, early identification, and related services to children with deaf-blindness, to assure that they may more effectively: 1) provide special education, etc. to children whom they are obligated to serve; 2) provide preservice or inservice training to paraprofessionals, professionals, or related services personnel preparing to serve or serving children with deaf-blindness; 3) provide replications of successful, innovative approaches; 4) provide activities to facilitate parental involvement; 5) provide consultative and counseling services to professionals, paraprofessionals, parents and others; and 6) promote the integration of children with deaf-blindness with children with other disabilities and without disabilities.

In addition, each grantee is directed to **EVALUATE THE EFFECTIVENESS OF SERVICES** both directly and through technical assistance to agencies, institutions, and organizations. Finally, the **COORDINATION OF SERVICES** is addressed in that the State Services for Deaf-Blind Program is expected to engage in on-going coordination with the state's education agency, the state's lead agency under Part H of IDEA, and other state agencies responsible for providing services to children with deaf-blindness (Federal Register, 1989; Federal Register, 1991). See Appendix.

**RECENT CHANGES**

1. The title of the law has been changed from the Education of the Handicapped Act (EHA) to the Individuals with Disabilities Education Act (IDEA).
2. The program focus re-emphasizes infants and toddlers with deaf-blindness and early intervention services as well as adding local education agencies (LEAs) and Part H lead agencies as beneficiaries of technical assistance.
3. To facilitate transition from educational to other service options, the age of youth with deaf-blindness has been expanded to include young adults. Competitive employment and independent living have been explicitly added as examples of these services.
4. The definition of children with deaf-blindness is:

"children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities. This term also means infants and toddlers with deaf-blindness.... individuals from birth through age 2 who are experiencing developmental delays in hearing and vision, have a diagnosed physical or mental condition that has a high probability of resulting in developmental delays in hearing and vision, or are at risk of having substantial developmental delays in hearing and vision if early intervention services are not provided." (Federal Register, 1991, p. 51585)

5. Information collected for the national census of children with deaf-blindness now also includes the educational and living settings in which services are provided as well as expanded requirements to specify the etiology.

6. Evaluation criteria for determining the amounts of the awards takes into consideration: a) the total number of children in the state, b) the total number of children with deaf-blindness in the state benefiting from the program, c) the relative cost of providing services, and d) the quality of the application (Federal Register, 1990, p. 156).

In general, the Services for Children with Deaf-Blindness Program grant activities should support interagency collaboration which results in developing coordinated, comprehensive, and longitudinal service plans for each individual with deaf-blindness including: early identification, appropriate educational programs, transition, assistance with competitive or supported employment, assistance with residential options for independent living, and a mechanism for tracking the individual with deaf-blindness throughout the service delivery system. These plans should reflect parental involvement and support throughout the planning and decision making process, as well as placement of the child in the least restrictive environment. Current research findings and exemplary practices should be utilized. Integration with age appropriate, non-disabled peers is a clear priority.

## WRITING APPLICATIONS

There are some general principles that apply when an application is written to secure funding. The Request for Proposals (RFP) instructions for the whole application should be read carefully and then followed exactly.

1. What is currently required by federal legislation (e.g., 34 CFR Part 307.11) and what educational practices are being supported (e.g., early intervention, transition)?
2. What criteria are used in the review process to determine the quality of applications and subsequent funding levels (i.e., selection criteria)?
3. How many points (out of 100) is each separate section of the application worth?
4. Does the application flow logically from section to section?
5. Is there enough detail?
6. How does the Services for Children with Deaf-Blindness plan fit into the state education agency (SEA) plan (e.g., goals; coordination with the Part H lead agency, Comprehensive System of Personnel Development, etc.)?
7. Is the application feasible considering resources and qualifications of key personnel?
8. What percentage of the budget goes for staff positions, technical assistance, travel, etc.?
9. Is the appearance of the application professional?
10. Are the critically important parts highlighted (e.g., boldface, underlined, indented)?

*The entire proposal should be neat, clean, and easy to read. Do not use jargon. Mail the proposal on time. Applications received after the due date will not be read. (Kiritz, 1980a; Kiritz, 1980b; Krathwohl, 1977; staff, 1988).*

**SPECIFIC SELECTION CRITERIA** - 34 CFR 307.33

For each section of an application, specific selection criteria from 34 CFR 307.33 are cited; points to consider for writing grants are listed; and examples and/or strategies are suggested.

| **A. JUSTIFICATION FOR THE PROJECT, EXTENT OF NEED, AND EXPECTED IMPACT.** |
|---|
| *The Secretary reviews each application to determine the justification for the proposed activities in each State, based on the extent of State need for and expected impact from the provision of services and technical assistance, including consideration of:* |
| 1. The age, number, and location of children with deaf-blindness in the State to whom the State is **not** obligated to provide a free appropriate public education under Part B of the IDEA, to whom the State is not providing special educational and related services under some other authority, and to whom the applicant proposes to provide services.<br>2. The specific actions needed for the provision of early intervention, educational, and related services to children with deaf-blindness based on the State's plan for delivery of services to students with handicaps required under Parts B and H of the IDEA.<br>3. The specific actions needed for the provision of technical assistance addressed by the project based on the State's plan for provision of technical assistance to providers of services to children with deaf-blindness.<br>4. The expected benefits to be gained by providing the early intervention, educational, and related services to children with deaf-blindness to be served by the project, their parents and service providers.<br>5. The expected benefits to be gained by meeting the technical assistance needs of service providers to be assisted by the project. (Federal Register, 1989, p. 30646; Federal Register, 1991, pp. 51586-51587). |

**POINTS TO CONSIDER:**

- What are the purposes of the authorizing statute?
- What are the objectives of this project?
- How will these objectives further the purposes of the authorizing statute?
- What needs are outlined by the authorizing statute?
- What needs does the applicant identify?
- How did the applicant identify those needs, i.e., what specific documentation or evidence does the application offer to support the applicant's assessment of need?
- Are the needs identified by the applicant consistent with the purposes of the authorizing statute?
- Does the applicant identify too many or too few needs for the proposed time frame and resources of the project?
- Are the outlined needs well defined so that the project can be focused on them, or are the outlined needs very generic?

**STRATEGIES:**

The statement of need and expected impact is critical. It should be related to the authorizing statute and to the goals of the state education agency, be of reasonable dimensions, be supported by data, be stated in terms of the recipients' needs and expected benefits, be developed with input from the Advisory Board, be free of jargon, be as interesting and as brief as possible, and make a compelling case for the funds requested.

As the basis for the statement of need and expected impact, **a needs assessment process** can be used to determine direct service and technical assistance and training needs for a specific state or region. The Teaching Research Assistance to Children and Youth Experiencing Sensory Impairments (TRACES) Project has developed such a process based on the current federal regulations (staff, 1991).

The first step in the process is to determine who is responsible for providing key **DIRECT SERVICES** to children with deaf-blindness in the state or region. Is the State Education Agency (SEA) mandated to provide services for children from birth through age 21? If not, who is responsible for providing these services (e.g., Department of Human Resources) and for what age groups (e.g., 0-2, 19-21)? If the SEA is not providing these key direct services for specified age groups, then the Services for Children with Deaf-Blindness program should be doing so. If the SEA does provide these key direct services from birth through age 21, then the Services for Children with Deaf-Blindness project may provide **TECHNICAL ASSISTANCE** to ensure quality programs.

The second step in the process is to determine the current condition of service delivery in the state or region. Each of the required 34 CFR Part 307.11 key services should be assessed regarding whether they are indeed available and if so, are they appropriate and adequate? If key services are either not available or not appropriate and adequate, then the Services for Children with Deaf-Blindness project should provide **TECHNICAL ASSISTANCE** to the responsible agencies, organizations, and institutions to ensure quality programs.

The TRACES Project long range needs assessment document can be used as a checklist for required key services. After completing the checklist with input from the advisory board and consumers, priorities must be set to determine the order in which specific key services will be addressed by the state or region. This, then, can be the basis for the Services for Children with Deaf-Blindness application.

Since it is important to relate the justification for your project to the authorizing statute, it may be helpful to develop a chart which presents the relationship between 1) the needs and objectives of your application and 2) the specific regulatory statements from 34 CFR 307.11.

**EXAMPLE:** If a particular SEA is only mandated to serve children ages 3-21; then the Title VI-C program might identify two of the needs as: 1) the direct service of identification of infants and toddlers with deaf-blindness **307.11(a)(1)(i)**, and 2) the need for technical assistance to the SEA in its in-service training program in the area of deaf-blindness **307.11(a)(2)(ii)**.

| | Need #1- identification | Need #2- technical assistance |
|---|---|---|
| 307.11(a)(1)(i) (Service to non-mandated children) | X | |
| 307.11(a)(2)(ii) (Services to mandated children) | | X |

## B. QUALITY OF SERVICES AND TECHNICAL ASSISTANCE

*The Secretary reviews each application to determine the quality of the plan to provide services and technical assistance in each state to be served including:*

1. The quality of the design of the project for providing each of the early intervention, educational, and related services described under 34 CFR 307.11 (a)(1) and for providing technical assistance as described under 34 CFR 307.11 (a)(2).
2. The extent to which the applicant's plan for providing services and technical assistance implements current research findings and exemplary practices including arranging for services that are age-appropriate for project participants, and providing for the maximum integration of children with deaf-blindness in the least restrictive environment.
3. How well the objectives of the project respond to the needs of children with deaf-blindness in the State, their parents, and service providers.
4. The extent to which the plan of management is effective and ensures proper and efficient provision of early intervention, educational, and related services, and technical assistance, and reflects an analysis of the service needs of children with deaf-blindness in the State.
5. How well the objectives of the project relate to the purpose of the program.
6. How the project will assist the State in developing and implementing the State's CSPD required under Parts B and H of the IDEA.
7. How the applicant will ensure that project participants who are otherwise eligible to participate are selected without regard to race, color, national origin, gender, age, or disabling condition.
8. The quality of the applicant's plan for providing early intervention, consultative, and training services for families of children with deaf-blindness as described in 34 CFR 307.11 (a)(1)(iii).
9. The quality of the applicant's plan to involve parents in the development and delivery of appropriate services to their children with deaf-blindness.
10. The extent to which services provided for children birth through two years of age meet the requirements of Part H of the IDEA." (Federal Register, 1989, p. 30646; Federal Register, 1991, p. 51587).

**POINTS TO CONSIDER:**

- Do the project objectives serve the purposes of the authorizing statute?
- How well is the project designed? Are project objectives consistent with stated needs? Are project activities consistent with project objectives? Are project objectives measurable?
- How will the applicant use its resources and personnel to achieve each objective?
- Has the applicant developed an effective management plan that will ensure proper and efficient administration of the project?
- Do project milestones represent a logical progression of times and tasks?
- Does the applicant propose a realistic time schedule for accomplishing objectives?
- Will the proposed activities accomplish the project's objectives successfully?
- Are the educational approaches planned based on sound research that indicates they will be successful for the population to be served?
- Does the project have clearly developed provisions for providing equal access to eligible participants who are members of traditionally underrepresented groups?
- Are the proposed facilities adequate for project purposes?
- Is the proposed equipment adequate for project purposes?
- Does the applicant have access to special sources of experience or expertise?

STRATEGIES:

**Project objectives** should serve the purposes of the authorizing statute. They are the expected outcomes of your proposed activities described in measurable terms. There should be at least one objective for each identified need and a projected timeline for meeting each objective.

**EXAMPLE:** If the state is only mandated to serve children ages 3-21, the Service for Children with Deaf-Blindness program could propose as two of the project's objectives: 1) to cooperate with the Part H lead agency in providing the direct service of identification of infants and toddlers with deaf-blindness **307.11(a)(1)(i)**, and 2) to provide technical assistance to the SEA in its' in-service training program in the area of deaf-blindness **307.11(a)(2)(ii)**.

| | Obj. #1- Identification | Obj. #2- Technical Assistance |
|---|---|---|
| 307.11(a)(1)(i) (Service to non-mandated children) | X | |
| 307.11(a)(2)(ii) (Services to mandated children) | | X |

**Project activities** are the means by which you propose to meet your objectives. They should flow logically from the needs and objectives, be sequential, clear, describe who is responsible for each one, and be reasonable considering the timeframe and resources of the application.

**EXAMPLE:** Possible activities for the sample objective #1 could be a) to provide information regarding the incidence of deaf-blindness, risk factors, and the state definition of deaf- blindness to the Part H lead agency and all other appropriate agencies and organizations; and b) to arrange for applicable agencies and organizations to have access to referral systems for diagnosis and other resources.

**EXAMPLE:** Possible activities for the sample objective #2 could be to coordinate with the state's Comprehensive System of Personnel Development (CSPD) to provide in-service training which incorporates strands on strategies for use with students with deaf-blindness in specific areas (e.g., communication) for the state special education conference.

If appropriate, the state plan for implementing Part H of IDEA as well as the state's CSPD plan can be referenced in this section. There should be citations to indicate that current research findings and exemplary practices have been used to develop project objectives and activities. The provision of consultative and training services for families of children with deaf-blindness should also be described.

The **management plan** contains: a detailed monthly timeline indicating all activities supporting each objective in the project, and a chart indicating the percentage of time allocation of key personnel to each project objective and activity.

should be at least one objective for each identified need and a projected timeline for meeting each objective.

**Example:** If the state is only mandated to serve children ages 3-21; the 307.11 program could propose as two of the project's objectives: 1) to cooperate with the Part H lead agency in providing the direct service of identification of infants and toddlers with deaf-blindness **307.11(a)(1)(i)**, and 2) to provide technical assistance to the SEA in its in-service training program in the area of deaf-blindness **307.11(a)(2)(ii)**.

| | Obj. #1 | Obj. #2 |
|---|---|---|
| 307.11(a)(1)(i) | X | |
| 307.11(a)(2)(ii) | | X |

**Project activities** are the means by which you propose to meet your objectives. They should flow logically from the needs and objectives, be sequential, clear, describe who is responsible for each one, and be reasonable considering the time frame and resources of the proposal.

**Example:** Possible activities for the sample objective #1 could be a) to provide information regarding the incidence of deaf-blindness, risk factors, and the state definition of deaf- blindness to the Part H lead agency and all other appropriate agencies and organizations; and b) to arrange for applicable agencies and organizations to have access to referral systems for diagnosis and other resources.

**Example:** Possible activities for the sample objective #2 could be to coordinate with the state's Comprehensive System of Personnel Development (CSPD) to provide in-service training which incorporates strands on strategies for use with students with deaf-blindness in specific areas (e.g., communication) for the state special education conference.

For the management part, a picture showing boxes and lines indicating relationships between you and other agencies or groups is helpful. Show cooperation lines, authority lines, and other relationships that allow the reader to see where you fit into the grand scheme of things. *The management plan* contains: a detailed monthly timeline indicating all activities supporting each objective in the project, and a chart indicating the percentage of time allocation of key personnel to each project objective and activity.

**Example:** Monthly timeline.

| | | Oct. '91 | Jan. '92 | May '92 | Sep. '92 |
|---|---|---|---|---|---|
| Obj. #1: identification **307.11 (a)(1)(i)** | act. a | ← | — | — | → |
| | act. b | | ← | — | → |
| Obj. #2: technical assistance **307.11 (a)(2)(ii)** | act. a | ← | — | → | |

**EXAMPLE:** Monthly timeline.

| | | Oct.'91 | Jan. '92 | May '92 | Sept. '92 |
|---|---|---|---|---|---|
| Obj.#1: identification **307.11(a)(1)(i)** | act. a | <--------- | ---------- | ---------- | ---------> |
| | act. b | | <--------- | ---------- | ---------> |
| Obj.#2: technical assistance **307.11(a)(2)(ii)** | act. a | <--------- | ---------- | ---------> | |

The **adequacy of the resources** section describes the resources of the facility where project services will be provided, the applicant agency's equipment and supplies which will be made available to facilitate or enhance the provision of project services, and the capability of the applicant in conducting project activities which are particularly relevant to the proposed objectives.

The **consumer participation** section must describe how the applicant will provide equal access and treatment for eligible project participants who are members of traditionally underrepresented or minority groups. It should also present a plan for involving participants and family members in the on-going review of project outcomes (e.g., as members of the Advisory Board).

## C. QUALITY OF KEY PERSONNEL

*The Secretary reviews each application to determine the qualifications of the key personnel the applicant plans to use on the project for the provision of services for children with deaf-blindness and technical assistance to agencies including:*

1. The qualifications of the project director.
2. The qualifications of each of the other key personnel to be used in the project.
3. The experience among key personnel... relevant to the provision of quality educational services to children with deaf-blindness in less restrictive environments.
4. The time that each person... will commit to the project.
5. How the applicant as part of its nondiscriminatory employment practices, will ensure that its personnel are selected for employment without regard to race, color, national origin, gender, age, or disabling condition. (Federal Register, 1989, pp. 30646-30647; Federal Register, 1991, 51587).

**POINTS TO CONSIDER:**

- Do the job descriptions adequately reflect skills needed to make the project work?
- Are the duties of personnel clearly defined?
- What relevant qualifications do the proposed personnel possess, especially the Project Director?
- Will proposed personnel need to be trained for the project?
- How much time will the proposed personnel actually devote to the project?
- To what extent does the applicant encourage employment applications from members of traditionally underrepresented groups?

**STRATEGIES:**

This section should contain clearly defined job descriptions of all personnel funded by the Services for Children with Deaf-Blindness project. It should list relevant qualifications for carrying out project activities including experience with children with deaf-blindness and the time commitment (FTE) to the project of each of the key personnel. If a position is 100% funded by the grant, then 100% of that person's time should be spent carrying out grant activities. This section must also describe the extent to which the applicant encourages applications for employment from persons who are members of traditionally underrepresented groups. Vitae listing experience and training related to the project objectives for each of the key personnel should be included in the appendices.

| D. EVALUATION PLAN |
|---|
| *The Secretary reviews each application to determine the quality of the evaluation plan for the project including the extent to which the applicant's methods of evaluation:* |
| 1. Are appropriate to the project.<br>2. To the extent possible, are objective and produce data that are quantifiable. (Federal Register, 1989, 30647). |

**POINTS TO CONSIDER:**

- Are the proposed methods of evaluation appropriate to the project?
- Will the proposed evaluation be objective?
- Will the proposed evaluation methods measure the effectiveness of project activities in meeting project objectives?
- Will the evaluation plan produce valid and reliable data concerning the accomplishment of project objectives?
- Does the evaluation plan measure the project's effect on the project audience?

**STRATEGIES:**

This section presents a plan for evaluating accomplishment of the objectives through measurable change and positive outcomes in children with deaf-blindness; a plan for evaluating and modifying activities during the course of the project; a list of qualifications of the person(s) who will do the evaluation; a list of objective, measurable criteria for success; a plan for how data will be gathered and analyzed; and a description of what reports will be produced.

Reference to accepted evaluation models, including controls for reliability and validity of data, is appropriate in this section. There should be a discussion of how the specific evaluation measures (e.g., participant satisfaction, new knowledge and skills gained, implementation of new knowledge and skills, and data on individual child change) will demonstrate that project activities have accomplished project objectives.

**EXAMPLE:** Objective #1: to cooperate with the Part H lead agency to provide the direct service of identification of infants and toddlers with deaf-blindness. **307.11(a)(1)(i)**

**Activity a**: The Outreach Consultant will provide informational brochures and videotapes on the incidence of deaf-blindness, risk factors, and the state definition of deaf-blindness to the Part

H lead agency and all other appropriate agencies and organizations throughout the duration of the project.

**Activity b**: The Outreach Consultant will assist applicable agencies and organizations to have access to referral systems for diagnosis and other resources on an individual child basis.

**DATA** will be collected by the Outreach Consultant for the annual child census of children with deaf-blindness between birth and age 21 in the state. The required report will be submitted. There will be an increase in the total number of children with deaf-blindness identified.

**EXAMPLE:** Objective #2: to provide technical assistance to the SEA in its in-service training program in the area of deaf-blindness. **307.11(a)(2)(ii)**

**Activity a**: The Project Coordinator will work with the state's Comprehensive System of Personnel Development (CSPD) to provide in-service training which incorporates strands on strategies for use with students with deaf-blindness in specific areas (e.g., communication) for the state special education conference.

**DATA** will be collected on: 1) the number of professionals, paraprofessionals, and related service personnel participating in the in-service training; 2) the knowledge gained by participants as demonstrated through pre-post tests; 3) the number of new communication strategies implemented in classrooms; and 4) increases in individual child responses to communication. There will be increases in all of the above measures. These data will be collected by the Project Coordinator and submitted in the year-end report.

| E. BUDGET AND COST EFFECTIVENESS |
|---|
| *The Secretary reviews each application to determine for technical assistance, and direct services where appropriate in each State to be served the extent to which:* |
| 1. The budgets are adequate to support the activities.<br>2. Costs are reasonable in relation to the objectives of the project.<br>3. Costs reflect the time anticipated to be spent by each staff member for the provision of technical assistance under 34 CFR 307.11 (a)(1) and 34 CFR 307.11 (a)(2) and costs for contracted and consultative services, travel costs, and other direct costs.<br>4. Costs reflect the time anticipated to be spent for administrative services. (Federal Register, 1989, p. 30647). |

**POINTS TO CONSIDER:**

- Is the budget adequate to support the project's proposed activities?
- Are overall project costs reasonable in relation to project objectives?
- How much of the project's total cost is devoted to administrative costs?
- Are budget items sufficiently justified?
- Is the budget excessive?

**STRATEGIES:**

The budget section should address both how program activities will fit in with other related activities in regard to shared funding (e.g., CSPD, Part H, etc.), and how program activities will be funded in the future (e.g., continuation grants, other sources). The budget detail should follow

the forms and instructions provided with as much specificity as required. This section should outline both a program budget which lists proposed costs for the major objectives and activities and a line item budget that is adequate to support the project activities and is supported with cost and pricing data. Finally, this section justifies how these expenditures will support project activities.

| F. COORDINATION |
|---|
| *The Secretary reviews each application to determine the adequacy of the applicant's procedures for initiating and maintaining coordination in each State to be served with:* |
| 1. Related activities funded from grants, contracts, and cooperative agreements awarded under Parts C, D, E, F, and G of the IDEA.<br>2. Relevant agencies, organizations and institutions having responsibility to deliver services to children with deaf- blindness in the State, including State education agencies and other service providers under Parts B and H of the IDEA and Section 1221 of Title I. (Federal Register, 1989, p. 30647). |

**STRATEGIES:**

The coordination section describes how the project activities will be coordinated with similar activities assisted under the IDEA and lists other organizations or institutions conducting activities essential to the effective implementation of the proposed project (e.g., certification programs in state colleges and universities, state plan for vocational rehabilitation). Written agreements from all cooperating agencies and letters of endorsement and support from relevant agencies should be included in the appendices. A list of Advisory Board members and their affiliations with relevant organizations and agencies can also be included.

**EXAMPLE:** The Services for Children with Deaf-Blindness application could include plans for coordination with: a) the Part H lead agency and all other appropriate agencies and organizations for purposes of identification **307.11(a)(1)(i)**, and b) with the state CSPD for in-service training activities **307.11(a)(2)(ii)**.

| G. DISSEMINATION |
|---|
| *The Secretary reviews each application to determine the adequacy of the applicant's procedures for disseminating significant project information within the State(s) to providers of services to children with deaf-blindness. (Federal Register, 1989, p. 30647).* |

**STRATEGIES:**

Dissemination activities to further achievement of the project objectives should be described including the contents, intended audiences, and timelines for production of each product to be disseminated as well as how project information will be distributed within the state(s).

**EXAMPLE:** Objective #1: to cooperate with the Part H lead agency to provide the direct service of identification of infants and toddlers with deaf-blindness **307.11(a)(1)(i)**.

**Activity a**: (1) The Outreach Consultant will provide informational brochures and videotapes on the incidence of deaf-blindness, risk factors, and the state definition of deaf-blindness to the

Part H lead agency and all other appropriate agencies and organizations throughout the duration of the project.

(2) The Outreach Consultant will make presentations on the incidence of deaf-blindness, risk factors, and the state definition of deaf-blindness to the Part H lead agency and all other appropriate agencies and organizations throughout the duration of the project.

(3) A project newsletter edited by the Outreach Consultant will be published four times a year. It will contain information on the incidence of deaf-blindness, risk factors, and the state definition of deaf-blindness. The newsletter will be distributed to teachers and parents of children with multiple disabilities, LEA special education supervisors and appropriate others.

**EXAMPLE:** Objective #2: to provide technical assistance to the SEA in its in-service training program in the area of deaf-blindness **307.11(a)(2)(ii)**

**Activity a**: The Project coordinator will work with the state's Comprehensive System of Personnel Development to provide in-service training which incorporates strands on strategies for use with students with deaf-blindness in specific areas (e.g., communication) for the state special education conference. Appropriate information will be disseminated to participants during the training by the Project Coordinator as follows:

(1) List of journal articles and books.
(2) List of resource materials (e.g., videotapes)
(3) List of model programs which might be visited.
(4) List of product suppliers (e.g., for augmentative communication devices).

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APPENDICES

## AUTHORIZING STATUTE REQUIREMENTS

(Federal Register, 1989; Federal Register, 1991)

34 CFR 307.11 WHAT TYPE OF SERVICES AND TECHNICAL ASSISTANCE BY STATE AND MULTI-STATE PROJECTS ARE CONSIDERED FOR SUPPORT UNDER THIS PART?

**(a)** The Secretary may provide financial assistance under this part to State and multi-State projects to support the following activities:

(1) Special education, early intervention, and related services, as well as vocational and transitional services, to children with deaf-blindness to whom State is not obligated to make available a free appropriate public education under Part B of the Individuals with Disabilities Education Act (IDEA) and to whom the State is not providing those services under some other authority. These services may include the following:

(i) The diagnosis and educational evaluation of children who are likely to be diagnosed as having deaf-blindness;
(ii) Programs of adjustment, education, and orientation for children with deaf-blindness;
(iii) Consultative, counseling, and training services for the families of children with deaf-blindness; and
(iv) Preparation of a coordinated plan for each child with deaf-blindness served, describing all the services provided under paragraphs (a)(1)(i) through (iii) of this section. These services must be in accordance with other Federal and State programs.

(2) Technical assistance to public and private agencies, institutions, and organizations providing early intervention, educational, transitional, vocational, early identification, and related services to children with deaf-blindness, to assure that they may more effectively:

(i) Provide special education and related services, as well as vocational and transitional services, to children with deaf-blindness to whom they are obligated to make available a free appropriate public education under Part B of the IDEA or some other authority and provide early intervention services under Part H of IDEA;
(ii) Provide preservice or inservice training to paraprofessionals, professionals or related services personnel preparing to serve, or serving, children with deaf-blindness;
(iii) Replicate successful, innovative approaches to providing early intervention, educational, or related services to children with deaf-blindness;
(iv) Facilitate parental involvement in the education of their children with deaf-blindness;
(v) Provide consultative and counseling services for professionals, paraprofessionals, parents, and others who play a direct role in the lives of children with deaf-blindness, to enable them to understand the special problems of those children, and to assist in the provision of appropriate services to those children; and
(vi) Promote the integration of children with deaf-blindness with children with other disabilities and without disabilities.

(3) The services described in paragraph (a)(1) of this section to children with deaf-blindness to whom a State is obligated to make available a free appropriate public education under Part B of the IDEA and to whom the State is providing these services under some other authority.

**(b)**(1) Each grantee under this section shall give priority in the use of project funds to the provision of services described in paragraph (a)(1) of this section and to the provision of technical assistance as described in paragraph (a)(2) of this section.

(i) Give first priority in the use of project funds to the provision of services described in paragraph (a)(1) of this section; and
(ii) Give second priority in the use of project funds to the provision of technical assistance to State education agencies, as described in paragraph (a)(2) of this section.

(b)(2) Any remaining funds may be used by the grantee, upon request of the State education agency, for pilot projects.

**(c)** Each grantee under this section shall:

(1) Develop and implement procedures to evaluate the effectiveness of services to children with deaf-blindness under paragraph (a)(1) of this section;

(2) Provide technical assistance to the public and private agencies, institutions, and organizations served under paragraph (a)(2) of this section in the development and implementation of procedures for evaluating the effectiveness of services they provide to children with deaf-blindness; and,

(3) Engage in on-going coordination with the State's education agency, the State's lead agency under Part H of the IDEA, and other State agencies responsible for providing services to children with deaf-blindness, in the provision of services under this section.

## SELECTION CRITERIA OVERVIEW

staff. (1988). Reviewing applications for discretionary grants and cooperative agreements: A workbook for application reviewers. pp. II-43 & 11-44. Washington, D.C.: Horace Mann Learning Center.

| | |
|---|---|
| MEETING THE PURPOSES OF THE AUTHORIZING STATUTE AND EXTENT OF NEED FOR THE PROJECT: | 1. What are the purposes of the authorizing statute?<br>2. What are the objectives of this project?<br>3. How will these objectives further the purposes of the authorizing statute?<br>4. What needs are outlined by the authorizing statute?<br>5. What needs does the applicant identify?<br>6. How did the applicant identify those needs, i.e., what specific documentation or evidence does the application offer to support the applicant's assessment of need?<br>7. Are the needs identified by the applicant consistent with the purposes of the authorizing statute?<br>8. Does the applicant identify too many or too few needs for the proposed time frame and resources of the project?<br>9. Are the outlined needs well defined so that the project can be focused on them, or are the outlined needs very generic? |
| PLAN OF OPERATION AND ADEQUACY OF RESOURCES: | 1. Do the project objectives serve the purposes of the authorizing statute?<br>2. How well is the project designed? Are project objectives consistent with stated needs? Are project activities consistent with project objectives? Are project objectives measurable?<br>3. How will the applicant use its resources and personnel to achieve each objective?<br>4. Has the applicant developed an effective management plan that will ensure proper and efficient administration of the project?<br>5. Do project milestones represent a logical progression of times and tasks?<br>6. Does the applicant propose a realistic time schedule for accomplishing objectives?<br>7. Will the proposed activities accomplish the project's objectives successfully?<br>8. Are the educational approaches planned based on sound research that indicates they will be successful for the population to be served?<br>9. Does the project have clearly developed provisions for providing equal access to eligible participants who are members of traditionally underrepresented groups?<br>10. Are the proposed facilities adequate for project purposes?<br>11. Is the proposed equipment adequate for project purposes?<br>12. Does the applicant have access to special sources of experience or expertise? |
| QUALITY OF KEY PERSONNEL: | 1. Do the job descriptions adequately reflect skills needed to make the project work?<br>2. Are the duties of personnel clearly defined?<br>3. What relevant qualifications do the proposed personnel possess, especially the Project Director?<br>4. Will proposed personnel need to be trained for the project?<br>5. How much time will the proposed personnel actually devote to the project?<br>6. To what extent does the applicant encourage employment applications from members of traditionally underrepresented groups? |
| EVALUATION PLAN: | 1. Are the proposed methods of evaluation appropriate to the project?<br>2. Will the proposed evaluation be objective?<br>3. Will the proposed evaluation methods measure the effectiveness of project activities in meeting project objectives?<br>4. Will the evaluation plan produce valid and reliable data concerning the accomplishment of project objectives?<br>5. Does the evaluation plan measure the project's effect on the project audience? |
| BUDGET AND COST EFFECTIVENESS: | 1. Is the budget adequate to support the project's proposed activities?<br>2. Are overall project costs reasonable in relation to project objectives?<br>3. How much of the project's total cost is devoted to administrative costs?<br>4. Are budget items sufficiently justified?<br>5. Is the budget excessive? |



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# APPENDIX E

# ETIOLOGIES AND CHARACTERISTICS OF DEAF-BLINDNESS

# Etiologies and Characteristics of Deaf-Blindness

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Traces

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# *Preface*

There are several disorders, syndromes, infectious diseases, and adventitious conditions that may result in an individual being deaf-blind. As a result of these various etiologies, an individual who is deaf-blind may exhibit a range of vision and hearing losses. Sensory loss may range from mild impairment to total loss of the ability to see and/or hear. Usually, one sensory impairment is more prominent than the other. At times, the condition may be a progressive one. Due to the subtly and progressive nature of some visual and auditory impairments, it is paramount that individuals working with persons with deaf-blindness have an understanding of these various disorders in order to effectively observe and assess for sensory loss. By being aware of the possibility of auditory and visual impairments and the characteristics associated with them, appropriate assessment, educational interventions and adaptations may be implemented in the classroom, home and community.

This monograph has been developed to assist State 622C Coordinators, administrators, educators, related staff and parents to gain a better understanding of the terminology and major causes of deaf-blindness. This monograph has been divided into two sections. The first section covers three chapters which provide basic information relating to definitions, anatomy and common disorders. The first chapter on Definitions and Terminology for Deaf-Blindness, will provide information on who is considered deaf-blind. Additional information will be given on terms commonly found in the vision and hearing literature which are used to describe specific visual and auditory impairments. In the second chapter, Normal Anatomy of the Eye and Ear, the different anatomical parts of the eye and ear and how they function are explained. This should assist the reader in understanding impairments which are discussed in later chapters. In Chapter 3, Common Disorders of the Eye and Ear, various disorders which frequently are referred to in Section II of the monograph are explained in detail.

In Section II of the monograph (Chapters 4 through 8) information is provided on specific conditions and syndromes which may result in visual and auditory impairments. For those individuals who are involved in maintaining the state census on students with deaf-blindness, the chapters are set up to closely resemble the categories found in the federal census. (The census refers to the annual identification and counting of individuals with deaf-blindness which occures in each state and qualifies the student with deaf-blindness to additional technical assistance activities). Conditions referred to in the census can be located in this section as well as other possible etiologies (see Table 1). This monograph divided these conditions and syndromes into five chapters: Rare Syndromes, Congenital Infections and Other Teratogens, Prematurity & Small for Gestational Age, Adventitious Conditions, and Other Causes of Deaf-Blindness. Each chapter contains information regarding etiology, general characteristics, specific visual and hearing impairments and outcomes for each specific syndrome and condition.

| Major Causes of Deaf-Blindness | |
|---|---|
| A. Syndromes<br>1. Down's<br>2. Trisomy 13<br>3. Usher's<br>4. Other (specify) | D. Congenital Prenatal Disfunction<br>1. AIDS<br>2. Herpes<br>3. Rubella<br>4. Syphilis<br>5. Toxoplasmosis<br>6. Other (specify) |
| B. Multiple Congenital Anomalies<br>1. CHARGE association<br>2. Fetal alcohol syndrome<br>3. Hydrocephaly<br>4. Maternal drub abuse<br>5. Microcephaly<br>6. Other (specify) | E. Post-natal Causes<br>1. Asphyxia<br>2. Encephalitis<br>3. Head injury/trauma<br>4. Meningitis<br>5. Stroke<br>6. Other (specify) |
| C. Prematurity as sole known cause | F. Other (specify) |

*Table 1 Major causes of deaf-blindness*

For readers who are using this monograph to assist them with the census, there are a few deviations regarding the categorization from the federal census categories. All syndromes on the census are located in Chapter 4 on syndromes in the monograph. (However, CHARGE association which is located under multiple congenital anomalies on the census is located under syndromes. (Although it is not technically a syndrome, it is commonly grouped with them.) On the census, congenital prenatal dysfunction and multiple congenital anomalies are grouped together in Chapter 5 on Congenital Infections and Other Teratogens. Prematurity on the census is found in Chapter 6 on Prematurity and Small for Gestational Age. All post-natal causes on the census are found under Adventitious Conditions (Chapter 7).

Section I

# *Foundations*

Prior to learning about various etiologies and educational considerations of teaching individuals who are deaf-blind, it is important to have a solid understanding of the definitions, key terms, anatomical structures, and disorders which are encountered in the deaf-blind field. This section will provide a foundation of information to assist the reader in understanding basic terminology and disorders.

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Chapter 1

# Definitions and Terminology Pertaining to Deaf-Blindness

A broad array of definitions are used across the nation in identifying infants, toddlers, children and youth as having concomitant visual and hearing impairments. Many of these definitions are based on a functional orientation which permits examination of the learner's sensory impairments in regard to their impact in particular educational environments, such as a program designed for students with a vision or hearing loss. Most states have adapted a definition similar to the one cited in IDEA (Individuals with Disabilities Education Act). This definition states:

> ...the term "deaf-blind", with respect to children and youth, means having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated in special education programs solely for children and youth with hearing impairment, visual impairment, or severe disabilities, without assistance to address their educational needs due to these dual, concurrent disabilities (IDEA).

Other states use definitions which are medically oriented and often include such descriptive diagnostic information as acuity and field loss for describing visual loss, and the particular frequencies and decibel levels of loss for an auditory impairment. Other technical terms (e.g., sensorineural loss, low vision) may be included as well.

To more fully understand these definitions and how they apply to individuals with deaf-blindness, a discussion regarding the terminology and definitions used in the field of vision and hearing ensues.

## Terminology Describing Visual Impairments

Several terms may be used to describe the type of visual impairment a person with deaf-blindness experiences. Some of these are legal definitions while others are derived from the educational field.

### Legal Definitions

***Legal blindness***

Central visual acuity of 20/200 or less in the better eye after correction or central visual acuity of more that 20/200 if there is a visual field defect in which the peripheral field is reduced to a angle of 20 degrees or less in the better eye (Koestler, 1976, p. 45).

Partially sighted (or partially seeing): Visual acuity between 20/70 and 20/200 after correction in the better eye. (Although this term is used in many state definitions, it is considered outdated and is not being used by practitioners).

To understand these definitions, two terms may need clarification:

***Visual acuity***
This refers to the ability to clearly distinguish forms, objects or symbols at specific distances (Gothelf, Rikhye, & Silberman, 1988). The term 20/200 means that the person with the visual impairment can see an object or symbol at 20 feet that a person with unimpaired vision can see at 200 feet. (For a more in-depth description of visual acuity, see Chapter 2, page 11).

***Field of vision***
The ability to see objects in the periphery of ones vision when looking straight ahead. Individuals with unimpaired vision can usually see objects within 180 degree arc when looking straight ahead. (For more information on fields of vision, see Chapter 2, page 11).

## *Definitions used in Education*

Other definitions have been developed by educators which are more functional and meaningful for programming. Many of these definitions have been adopted into state and federal definitions.

***Visual Impairment (visual handicapped)***
This term encompasses a wide range of vision loss which can include deficits in acuity, field loss, ocular motility, or color perception. The visual impairment may be permanent or temporary. The term visual handicapped is often used synonymously with the term visual impairment to refer to a vision loss which even with correction, adversely affects a child's educational performance (P.L. 94-142).

***Blind***
Individuals who are totally without vision or who have light perception only. In the educational field, this term refers to children who use other senses (i.e. hearing and touch) as primary channels for learning or receiving information.

***Light perception only***
Individuals who are without vision, but can perceive light.

***Low vision***
This is a broad term which is used to refer to individuals who have significant visual impairments, but still have usable vision. Vision is still used as a primary channel for learning or receiving information. Although the visual impairment continues after correction, visual functioning may increase with the use of optical aids, environmental modifications or and training (Corn, 1980; Scholl, 1986).

***Visual functioning***
This refers to how well a person uses the vision he or she has. Visual functioning is considered a learned behavior which is not necessarily reflected by visual acuity. It is possible for a student to have poor visual acuity and good visual functioning, or

visa versa (Gothelf, Rikhye & Silberman, 1988). Individuals who fail to use their vision in an efficient or meaningful way have poor visual functioning and are often included in functional definitions describing visual impairments.

***Cortical Visual Impairment (Cortical Blindness)***
The visual cortex of the brain or the visual pathways to the brain are damaged. This results in varying visual impairments, depending upon the location of damage in the brain. The anatomy and physiology of the eye is not impaired.

## *Terminology Describing Auditory Impairments*

There are several terms which are used to describe the type and severity of hearing loss a person may be experiencing. Some terminology is legally used to define an auditory impairment (i.e. deafness, hard of hearing), other terminology classifies the hearing loss by the location of damage. Auditory impairments can be further classified by the severity of loss. Other terms can be found as well.

### *Legal and Educational Definitions*

Educators have adopted the terms deaf and hard-of-hearing to denote the student's ability to function in the classroom. These terms are found in federal and state definitions. In IDEA, they have been defined as follows:

***Deaf***
A hearing impairment which is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification, and which adversely affects educational performance.

***Hard of hearing***
A hearing impairment whether stable or progressive, which affects a child's educational performance, but is not included under the definition of deaf.

Hearing impairments may also be described in terms of the location of the impairment in the auditory system. The hearing loss may be described as a conductive, sensorineural, mixed, and/or central loss. These terms are defined as follows:

***Conductive hearing loss***
An obstruction, infection, structural abnormality or other condition in the outer or middle ear which results in a hearing loss.

***Sensorineural hearing loss***
Impairments in the inner ear or auditory nerve which extends from the inner ear to the brainstem which result in a hearing loss.

***Mixed hearing loss***
A combined conductive and sensorineural hearing losses.

***Central hearing loss***
A hearing loss resulting from deficits in the areas of the brain (auditory cortex) that receive and process auditory input, or the pathways going from the brainstem to the auditory cortex.

Individuals who fail to use their hearing in an efficient or meaningful way are often included under a functional definition of sensory impairment.

### *Degree of Hearing Loss*

The severity of a hearing impairment is often described in terms of loudness (decibels) and pitch (frequency or Hertz). An audiometer (electronic instrument) permits measurement of hearing levels at varying decibel levels across low and high frequencies (which are recorded as Hertz or cycles per second). From these results the following levels of severity have been delineated:

***Normal***
Hearing level 0-20 decibels

***Mild hearing loss***
Hearing level 21-40 decibels (Can hear conversational speech, but will have difficulty hearing distant or faint sounds. Amplification may be needed.)

***Moderate hearing loss***
Hearing level 41-60 decibels (Can hear conversational speech 3 to 5 feet away. Will probably need a hearing aid and auditory training)

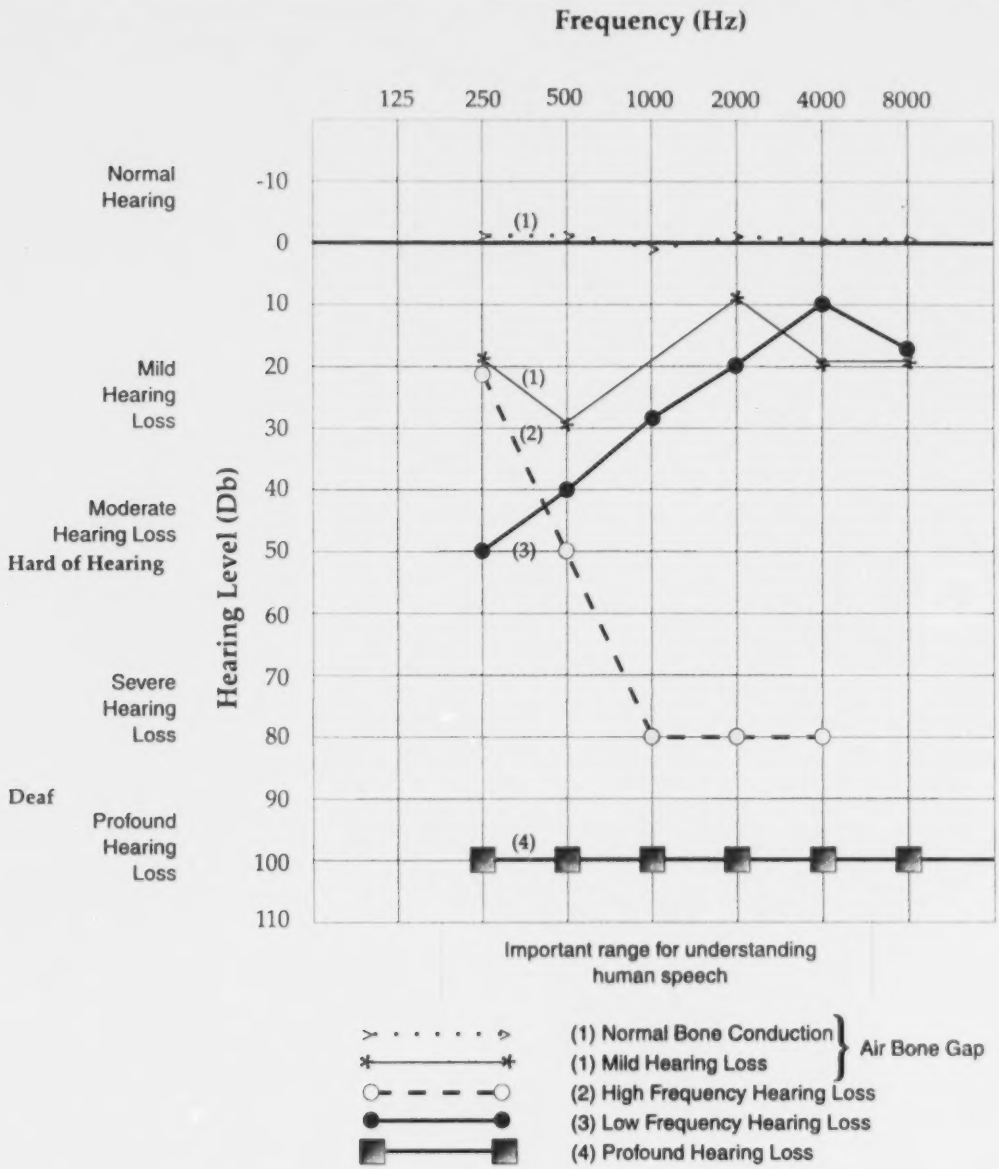
***Severe hearing loss***
Hearing level 61-80 decibels (May hear a loud voice at about one foot and be able to identify environmental noises. May be able to determine vowels, but not consonants.)

***Profound hearing loss***
Hearing loss >80 decibels (May hear loud sounds, but hearing in not a primary modality used for receptive communication) (Hamre-Nietupski, Swatta, Veerjusen and Olsen, 1986)

Hearing losses can be depicted on a audiogram (see Figure 1). As the decibel level required for an individual to initially hear a sound at a certain frequency level increases, the hearing loss increases. The amount of hearing loss may also vary across frequencies. A person may have a low frequency hearing loss in which he or she is unable to hear low sounds or more frequently, a high frequency loss may be present.

## *Terminology Describing Age of Onset*

Further classification may be made in terms of the age of onset of the hearing impairment. This has important implications since the earlier the hearing loss manifests itself in a child, the more disabled he or she is likely to be in terms of language development (Hallahan & Kauffman, 1988).




Adapted from, Keele (1983). *Developmentally disabled child*, p. 142. New Jersey: Medical Economic Books.

*Figure 1 Audiogram*

***Congenitally deaf***
Born deaf.

***Adventitiously deaf***
Deafness acquired after birth.

***Prelingual deafness***
Deafness prior to speech or language development.

***Postlingual deafness***
Deafness occurring after speech and language is developed. The age which differentiates prelinguistic from postlinguistic deafness has changed through the years due to the shifting emphasis on the importance of receptive language. Presently 18 months is commonly used as dividing point, although some argue that it should be changed to 12 or 6 months (Meadow-Orlans, 1987).

## *Visual and Auditory Impairments Combined*

Due to the broad range of both visual and auditory losses any combination of sensory impairment is possible. Individuals may have:

- auditory impairment and visual impairment with vision loss being the primary disability;
- auditory impairment and vision impairment with auditory impairment as the primary disability;
- auditory impairment and blindness;
- deafness and visual impairment, and
- deaf-blindness (Roberts, Helmstetter, Guess, Murphy-Herd & Mulligan, 1984).

The majority of those who are classified as having concomitant visual and hearing impairment have some useful residual vision or hearing. Total absence of vision and hearing is very rare. The following graph depicts most of the possible combinations which may occur with an individual who is deaf-blind (see Figure 2). Concomitant vision and hearing loss may also be conceptualized as occurring congenitally or adventitiously (see Figure 3, page 8).

Often individuals who are deaf-blind also have other impairments as well. These may be additional physical disabilities, mental retardation or other types of disabilities (see Figure 4 page 9).

Overall, there are many different uses of terminology associated with describing the specific visual and auditory impairment of an individuals who is deaf-blind. By better understanding these terms, administrators, educators, and related staff will be better equipped to identify those who are deaf-blind and meet their needs.

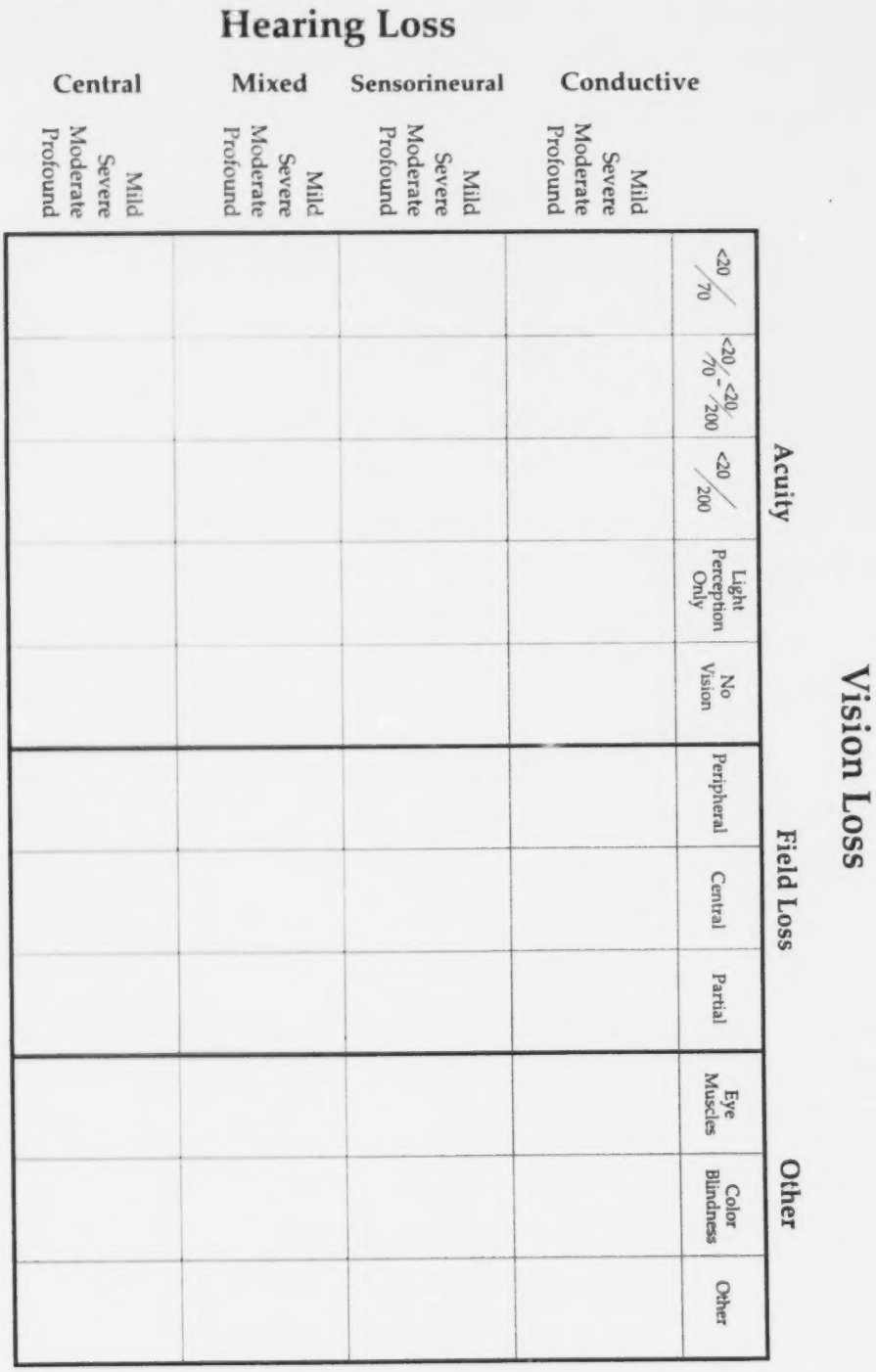



*Figure 2 Combinations of vision and hearing impairments*

## Individuals with Dual Sensory Impairments

### Onset

- Congenitally Deaf-Adventitiously Blind
- Congenitally Deaf-Blind
- Adventitiously Deaf-Blind
- Adventitiously Deaf-Congenitally Blind

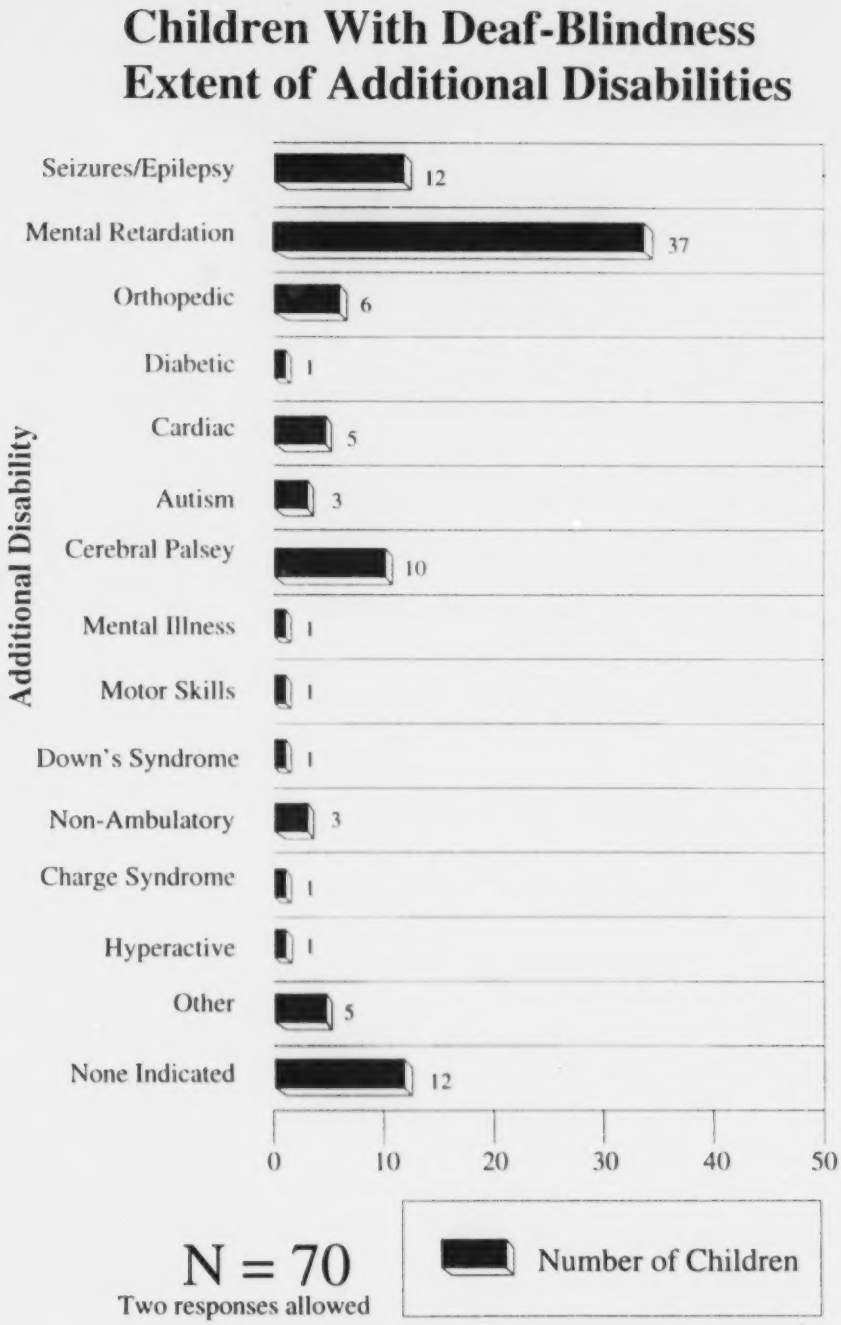
### Degrees

- Hard of Hearing-Blind
- Hard of Hearing-Visually Impaired
- Deaf-Visually Impaired
- Deaf-Blind

### Conditions

- Stable, Progressive Temporary

*Figure 3 Differences in characteristics*




(Reprinted with permission from Morgan, B., (1984). The INSITE Model. U.S. Office or Education, Bureau of Education for the Handicapped. Washington, D.C.)

*Figure 4 Additional physical disabilities*

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Chapter 2

# Normal Anatomy of the Eye and Ear

The eyes and ears have complex anatomical structures and physiological processes which are needed for proper functioning of these sensory organs. An understanding of the basic anatomy and physiology of the eye and ear is needed as a foundation for later discussion regarding various abnormalities in the eye and ear which may result in visual and auditory impairments.

## The Visual System

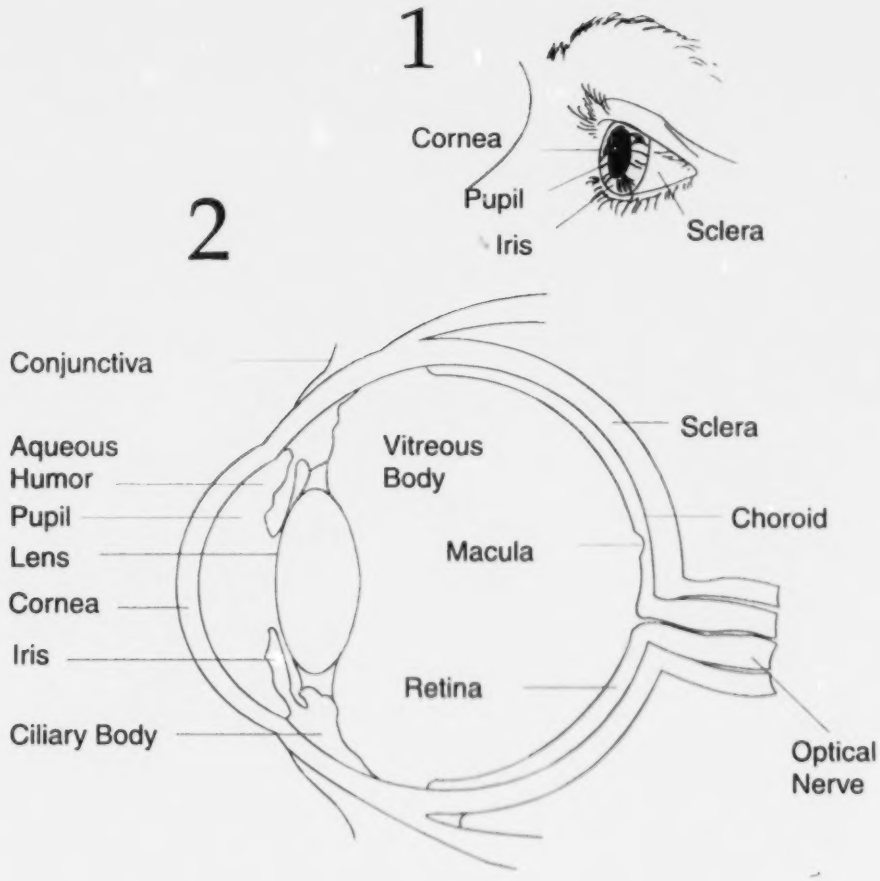
The visual system may be divided into three areas: (1) the eye (and its muscles), (2) the visual pathways to the brain and (3) the visual cortex. The structures of the eye collect and focus light energy into an image, and then convert the image into an electric-chemical impulse. The visual pathways transmit the electric- chemical impulses to the visual cortex. The visual cortex (located in the brain) interprets the impulse and relays it to other higher cerebral centers (Biglan, Van Hasselt & Simon, 1988).

### The Eye

The eye can be divided into three layers consisting of the outer layer (containing the sclera and cornea), the middle layer (containing the choroid, iris, and ciliary body) and the inner layer (the retina) (see Figure 5). Within these three layer are located internal structures and fluids which refract the light to achieve a clear image.

The outer layer of the eye consists of the cornea, which covers one sixth of the anterior outer portion of the eye, and the sclera which covers the remaining five-sixths of the eyeball. The cornea is clear and refracts light rays as they enter the eyes. It also protects the inner portions of the eye. The sclera is the white part of the eye. It wraps around the entire eyeball except for where the cornea is located. It also serves as protection to the inner contents of the eye (Jose, 1983).

The middle layer of the eye is the uveal tract which consists of the iris, the ciliary body and the choroid. The iris is the colored part of the eye which has an opening in its center, known as the pupil. The iris controls the amount of light entering the eye by regulating the size of the pupil. In dim light, the pupil dilates (enlarges) to allow more light to enter the eye. In bright light, the pupil constricts (becomes smaller) to allow less light into the eye.




*(1) Surface anatomy of the eye. (2) Internal structure. From Fig 35-1, Bleck & Nagel (1982) reprinted with permission of Allyn and Bacon.*

*Figure 5 Anatomy of the eye*

Directly continuous with the iris is the ciliary body. Part of the ciliary body is known as the ciliary muscle. It controls the curvature (shape) of the lens by relaxing and contracting the fibers that maintain the tension on the crystalline lens (Ward, 1986). The crystalline lens is located directly behind the pupil. Through the actions of the ciliary muscle, the eyes accommodate (focus for near and distant objects). The other major function of the ciliary body is the production of aqueous humor through the action of the ciliary processes. The aqueous humor is continually produced, fills the anterior portion of the eye, and is reabsorbed through the anterior chamber angle (angle between the iris and cornea). The aqueous humor brings nourishing materials to the cornea and lens and removes waste products.

The choroid is in the posterior part of the eye, located between the sclera and the retina. It contains many blood vessels and provides nutrients to the retina.

The inner (or neural) layer of the eye consists of the retina. It is a light sensitive membrane which converts the light rays to electrical impulses. The retina is composed of approximately 125 million photoreceptors categorized into rods and cones. The rods and cones are responsible for the conversion of light rays to electrical-chemical impulses (Ward, 1986). The rods are sensitive to low intensity illumination (dim light), and can detect gross form and movement. Rods are primarily responsible for peripheral vision. The cones are sensitive to high intensity illumination (day light), and detect fine detail and colors. On the retina there is a small central area in which most of the cones are located. This area is known as the macula. In the center of the macula is the fovea (the area of most distinct vision). The fovea and the macula together are responsible for most central vision.

Between the lens and the retina is a chamber which is filled with vitreous humor. Vitreous humor is clear gelatinous substance which aids in keeping the shape of the eyeball.

Several of the structures are responsible for refracting the light onto the retina and producing a focused image. The light rays pass through the cornea which produces the greatest amount of refraction of light rays. The light rays then pass through the aqueous humor and the pupil to the lens. The lens provides the second greatest amount of refraction to further refine and focus the light. The light rays pass through the vitreous humor and are further refracted. Finally the image appears upon the retina. From that point the image is carried to the brain along the optic nerve and through optic pathways.

### *The Extraocular Muscles*

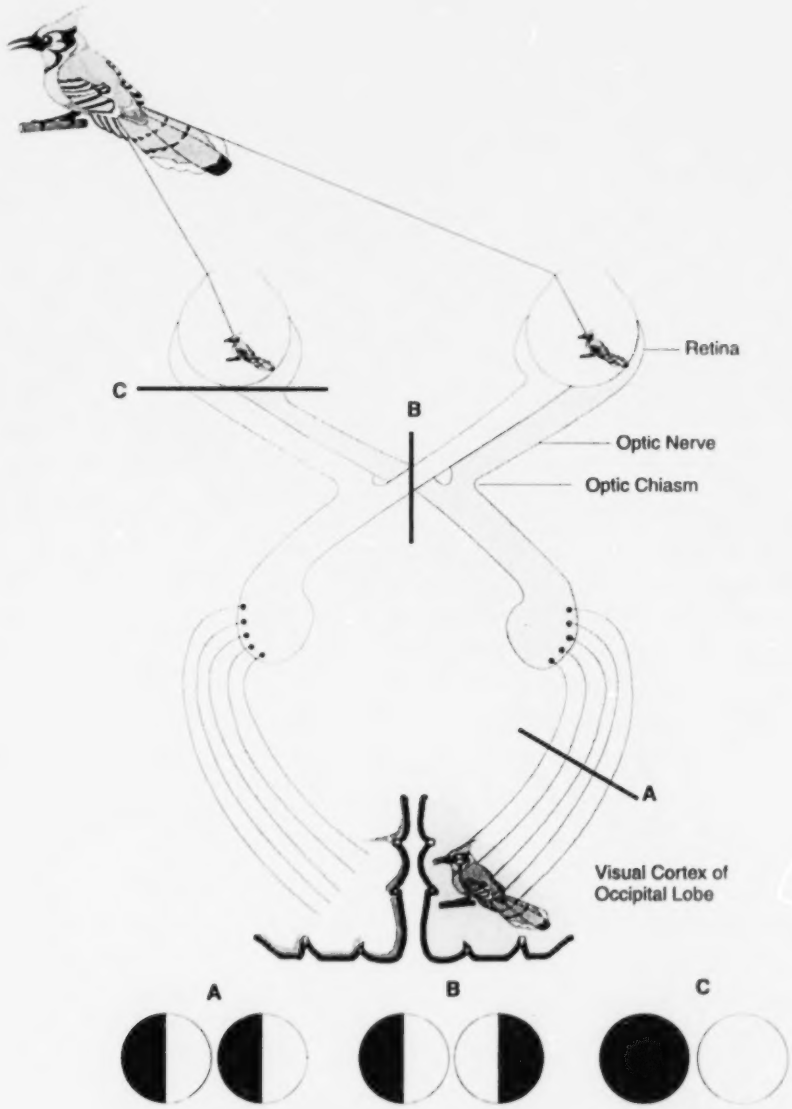
Each eye movement is controlled by six muscles surrounding the eyeball (extraocular muscles). These muscles can move the eye up, down, diagonally and sideways. One of the requirements for single binocular vision is the coordinated movement of both eyes by the extraocular muscles (Rosenthal, 1982). Additionally, depth perception is facilitated by alignment of two eyes.

### *The Visual Pathways*

After the image has been converted into electro-chemical impulses by the retina, the impulses travel down the optic nerves which are located posteriorly behind each eyeball. Part of the fibers of each optic nerve cross each other at a point known as the optic chiasm. The impulse continues through the rest of the optic tracts, optic radiations and to the posterior part of the brain (occipital lobe). This occurs in such a way that the visual field on the right side of the body is transmitted to the left side of the brain. The visual field on the left side of the body is transmitted to the right side of the brain (see Figure 6).

### *The Visual Cortex*

In the posterior portion of the brain is an area known as the visual cortex (located in the occipital lobe). This area of the brain permits recognition of the transmitted impulses. From this area, the impulse is transmitted to higher cerebral centers. In




An abnormality at various points along the route (upper figure) will lead to different patterns of visual loss (lower figure). These are illustrated:
A) abnormality at the cortical pathway;
B) damage to the optic chiasm;
C) retinal damage.

*Figure 6 Visual pathway*

these higher cerebral centers, visual input is integrated with other sensory input to allow a person to recall or remember perceived images.

# The Auditory System

The auditory system may be divided into four areas: the outer ear, the middle ear, the inner ear and the central auditory system. The ear collects sound waves and converts them into electro-chemical impulses. These impulses exit the ear via the eighth cranial nerve (auditory nerve) and are transmitted to the auditory cortex of the brain.

## The Outer Ear

The outer ear is composed of the auricle (pinna) which is the visible part of the ear, and the external auditory canal (see Figure 7). The auricle collects sound waves and transmits them through the external auditory canal. The external auditory canal is lined by skin and contains hair and cerumen (wax). The function of cerumen is to lubricate and prevent infection of the skin, and to decrease sensitiviey of the canal to wind and cold.

## The Middle Ear

The middle ear is bordered on one side by the tympanic membrane (eardrum) and on the other by the oval and round window membranes, eustachan tube orifice, and the boney medial, superior, and inferior walls of this space. Contained in this air filled space within the temporal bone are three connected bones (or ossicles) known as the malleus (hammer), incus (anvil) and stapes (stirrup). The malleus is attached to the tympanic membrane and the stapes is directly attached to the oval window. When a sound occurs, air vibrations enter the outer ear and cause the tympanic membrane to move. The tympanic membrane converts sound waves to mechanical vibrations by causing the malleus, incus and stapes to mechanically vibrate. The vibrations of these three bones (ossicles) result in moving the oval window membrane, the inner ear fluids, and the round window membrane.

## The Inner Ear

The inner ear consists of two main sections: the cochlea (responsible for hearing) and the vestibular mechanism (responsible for sense of balance). The cochlea has the appearance of a snail shell and is a system of coiled tubes which are filled with fluid. In the the cochlea is the Organ of Corti which contains auditory receptor cells, known as hair cells. When the oval window membrane vibrates from the motion of the stapes, waves are transmitted within the fluid of the cochlea to the round window membrane. This wave motion moves the hair cells which then stimulate electro-chemical impulses. The type and location of movement of the hair cells determines the auditory information which is transmitted out of the inner ear by the cochlear division of the VIII cranial nerve (auditory nerve).

## The Central Auditory System

Once the electrical impulses via the auditory nerve are transmitted to the first synapse at the brainstem, other pathways of the central auditory system transmit the electrical impulses to the auditory cortex. Some of these impulses cross over to the

opposite side of the brain while others stay on the same side. The information is received in an area of the brain known as the temporal lobe. From here, other higher centers of the brain will process the sounds.

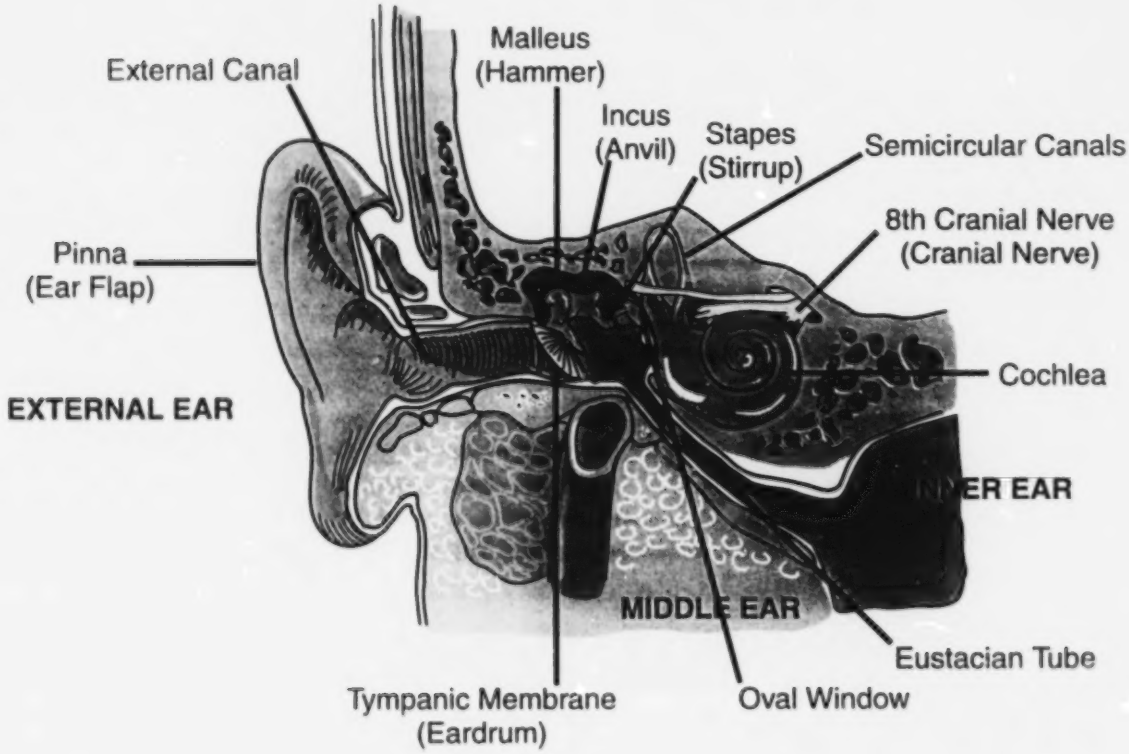



*Figure 7 General view of the ear*

Chapter 3

# Common Disorders of the Eye and Ear

There are several common disorders of the eye and ear which are frequently encountered in children and youth with deaf-blindness. This chapter will discuss some of the most frequently occurring disorders and their impact upon vision and hearing. This will assist the reader in understanding the visual and auditory impairments of persons who are deaf-blind as well as provide a reference for the various etiologies described in the second section of the monograph.

## Common Visual Disorders

Visual disorders can be grouped together by their structure and function. Categories of disorder by structure include: disorders of the outer layer (cornea, and sclera), middle layer and surrounding chambers and fluids (aqueous humor, iris, ciliary body, lens and vitreous humor) and inner layer (retina). General eye malformations, disorders of the visual pathway and disorders of the visual cortex follow. A section titled "Disorders affecting functional vision" includes problems of visual acuity, visual field deficits, ocular motility abnormalities, deficits in reflexive visual processes, and color blindness (see Figure 8).

### Disorders of the Outer Layer of the Eye

#### *Diseases of the cornea*

Diseases of the **cornea** can result in serious visual impairment ranging from blurring of vision to total blindness. Since the cornea refracts light rays, a lesion on the cornea may result in blurred vision. If scarring or perforation from an ulceration occurs, blindness can result. Usually prompt medical treatment permits avoidance of permanent damage (Jose, 1983).

#### *Keratoconus*

**Keratoconus** is a cone shaped cornea which results in a distortion of the entire visual field. This rare disorder usually begins during adolescence and is slowly progressive. Initially, a mild vision loss with myopia (nearsightedness) and astigmatism occurs. Bilateral thinning, scarring and stretching of the center of the cornea occurs and visual acuity then worsens (Apple & Rebb, 1991). Frequent changes of glasses or contacts are needed as the visual acuity worsens. If left untreated, this condition can slowly progress to the point that the cornea ruptures, resulting in blindness. However, contact lenses may improve visual acuity in the

early stages and surgery can be performed. This disorder has been found to occur in individuals with congenital Rubella and Down syndrome (Lucas, 1989).

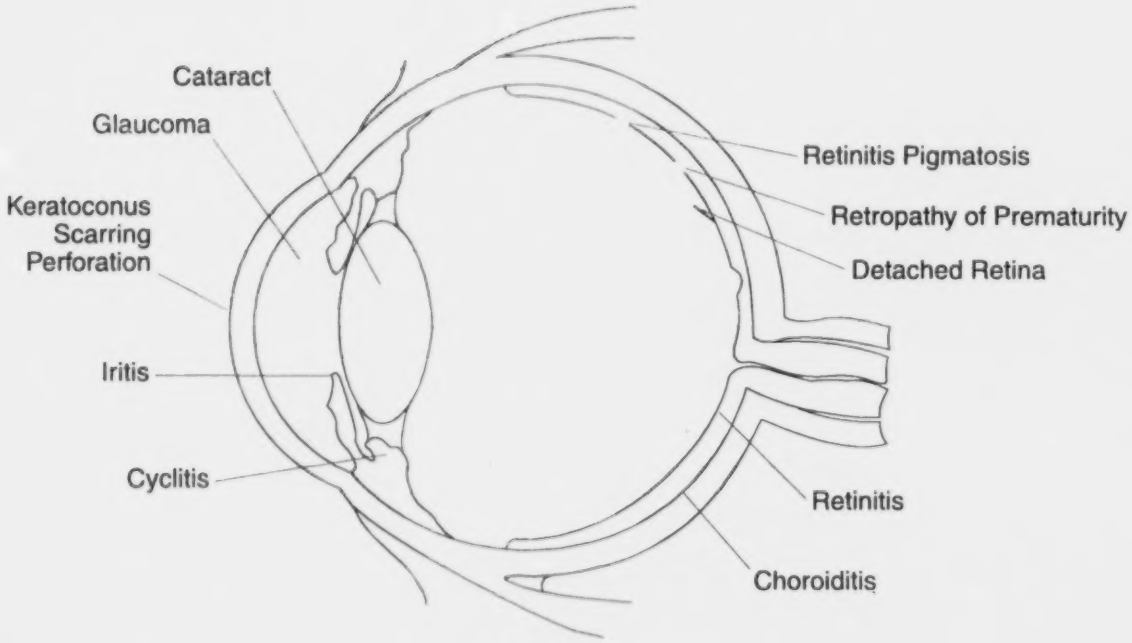



*Figure 8 Common disorders of the eye and their location*

## *Disorders of the Middle Layers of the Eye*

There are several disorders of the middle layers of the eye and surrounding structures and fluids. Some of these include glaucoma, cataracts, and uveitis.

### *Glaucoma*

Glaucoma is an abnormal increase in intraocular pressure which can damage the eye and visual functioning. There are several types of glaucoma which all involve an imbalance between production and outflow of the aqueous humor. One category of glaucoma is known as primary glaucoma in which there is no other causative agent other than the glaucoma, itself. This category of glaucoma is typically due to a blockage in the area of the eye that the aqueous humor exits. The blockage of the outflow of aqueous humor results in increased intraocular pressure. If this increase

in intraocular pressure is permitted to progress, the optic nerve will be damaged, resulting in loss of visual acuity, field loss, and/or blindness (Berkow, 1987; Martyn & DiGeorge, 1987). Congenital glaucoma, which is glaucoma occurring from birth, is considered a primary type of glaucoma.

When the glaucoma develops from another eye disorder (such as uveitis or cataracts) or disorders involving other organ systems, it is known as secondary glaucoma. This form of glaucoma is often caused by blockage of the flow of aqueous humor.

As discussed in subsequent chapters, glaucoma may be associated with other conditions such as congenital infections (STORCH), adventitious conditions (e.g. trauma, tumors), retinopathy of prematurity and some syndromes.

The major signs of glaucoma in infants include eye enlargement, tearing, photophobia, corneal clouding, twitching of the eye muscles and intense eye pain. After age three, the sclera and cornea are less expandable and signs of pressure elevation are different. The child or adolescent may have no symptoms even with pressure high enough to cause visual loss.

When the individual is born with glaucoma (congenital glaucoma), surgical intervention is necessary to correct the blockage and prevent optic nerve impairment. For glaucoma which develops after birth, eye drops can usually control the condition and may be all that is required. In a few cases, surgery may be necessary. For individuals who have secondary glaucoma, the other condition will need to be treated for glaucoma treatment to be successful. In this case, medication or surgery may be indicated.

*Cataract*

A **cataract** is any opacification (clouding) of the crystalline lens of the eye. Cataracts may be present at birth (congenital cataracts) or develop later. Its effect on vision varies depending on the size, position and density of the cloudy area. Some cataracts involve pinpoint areas which do not interfere with visual acuity. Other cataracts result in decreased visual acuity with blurred vision. If the opacity is more centrally located, near vision may be affected and vision may be worse in bright light. Those opacities located in the outer portion of the lens may result in poor color discrimination due to the abnormal scattering of light rays (Jose, 1983). As the cataract progresses, it may become so dense that blindness results.

As the cataracts are developing, frequent changes in eyeglass prescription may help assist with maintaining useful vision. When cataracts progress to the point that useful vision is gone, surgery is performed to removes the lens. When an infant has congenital cataracts, surgery within a few months of birth is often advised to allow for proper development of visual responses. After cataract surgery, the individual will need to wear glasses, contact lenses or may have a prosthetic lens implant.

Cataracts are present in a wide range of developmental disorders. Some of these include congenital infections (e.g. CMV, toxoplasmosis, rubella, and herpes) and syndromes (Trisomy 18, Trisomy 13, Down syndrome, Cockayne, Crouzon, Refsum and Usher syndromes). Cataracts may also occur from trauma or drugs (steroids)

and are associated with metabolic disorders. A special type of lens abnormality called "cataract of prematurity" may occur in newborns, but the cloudy areas usually disappear after a few weeks (Martyn & DiGeorge, 1987).

***Uveitis***

Uveitis is an inflammation of the uveal tract (which consists of the iris, ciliary body and choroid). It includes **iritis** (inflammation of the iris), **iridocyclitis** (inflammation of the iris and ciliary body), **cyclitis** (inflammation of the ciliary body) and **choroiditis** (inflammation of the choroid). Posterior uveitis includes **chorioretinitis** (inflammation of the choroid and retina) and **retinitis** (inflammation of the retina). (These two conditions are typically included under uveitis although they are anatomically posterior to the uveal tract.) Uveitis may be chronic or acute, often resulting in diminished or hazy vision. Black floating spots may be present. Severe pain, redness, and photophobia can occur in iritis and iridocyclitis. Complications such as cataracts, glaucoma and retinal detachment may result (Berkow 1987).

Uveitis has been present in children with such congenital infections as herpes, rubella, syphilis, toxoplasmosis, and CMV. Individuals with AIDS who have acquired one of these infections may also develop uveitis (Knox, 1987). It is important to diagnosis uveitis early. Treatment of uveitis consists of corticosteroid medication

## *Disorders of the Inner Layer*

There are several disorders of the retina which negatively impact on vision. These can be divided into retinal dystrophies, retinopathy of prematurity, and retinal detachments.

***Retinal dystrophies (retinitis pigmentosa)***

Retinal dystrophies are lesions of the retinal cones, rods and pigments. The main group of retinal dystrophies are known as retinitis pigmentosa (RP). In retinitis pigmentosa, retinal degeneration occurs and melanin pigment migrates into the retina and deposits itself. The condition first begins with the rods being slowly destroyed, starting at the midperiphery. This results in night blindness and progressive loss of the peripheral field of vision. This continues to worsen and contracts from the periphery, leading to tunnel vision. Cone degeneration also occurs and as it progresses, the tubular vision further constricts to the point that central vision is reduced and difficulties occur seeing in the day as well. Both eyes are usually affected with this hereditary condition and onset is between ages of ten and twenty (Lucas, 1989). Vision loss is gradual with adolescents often exhibiting difficulty traveling at night, difficulty moving from outdoors to indoor lighting as well as doing certain activity such as playing sports due to a loss of peripheral vision. As the condition progresses, total blindness can result later in life (Apple & Rabb, 1991).

Several atypical forms of retinitis pigmentosa have been found in which the symptoms and course of the condition are different than the classic form just described. In some forms of atypical retinitis pigmentosa, degeneration begin centrally. With these, the macula is involved which results in deficits of central

vision, poor acuity and color vision abnormalities. These may progress to the periphery and result in degeneration in that area as well.

Certain syndromes may have typical retinitis pigmentosa (e.g. Usher syndrome) or atypical retinitis pigmentosa (e.g. Alstrom syndrome). There is no effective treatment at this time for either typical or atypical retinitis pigmentosa.

***Detached retina***

When an individual has a **detached retina**, the retina separates from its supporting structures and atrophies. Depending on the cause of the detached retina, the early symptoms are usually minimal. The individual may see a bright flash of light and possibly floaters that look like black dots or spider webs. As the detached retina passes over the macula, vision is blurred (Apple & Rabb, 1991). A scotoma (blind area) will develop in the field of vision which corresponds to the area of detachment (Jose, 1983). Typically, the detachment occurs from fluid accumulating under the retina which push it away from the choroid. This may occur from other ocular conditions such as retinopathy of prematurity, congenital infections (such as toxoplasmosis), general physical conditions (such as diabetes or head trauma) or after cataract surgery. If the individual is prone to retinal tears or detachment, rough physical activity (trampoline play) must be avoided.

When a retinal detachment occurs, the individual will need to have surgery as soon as possible to reattach the retina.

***Retinopathy of prematurity (ROP)***

ROP (previously known as retrolental fibroplasia) consists of an abnormal growth of blood vessels which occurs in the immature retina (Biglan, Van Hasselt, & Simon, 1988). About 90% of the cases are mild and spontaneous regression of these abnormal blood vessels may occur with minimal scarring and little to no visual loss (Flynn, 1987). In more severe causes, the abnormal blood vessels extend into the vitreous and may cause retinal detachment, severe visual loss and/or blindness (Biglan, Van Hasselt, & Simon, 1988).

Retinopathy of prematurity is thought to develop from the premature infant being exposed to high levels of oxygen in incubators. However, the condition has been present in premature infants not exposed to these oxygen levels (Berkow, 1987). Children with retinopathy of prematurity have a higher risk of myopia, strabismus and glaucoma.

## *Eye Malformations*

***Microphthalmus, anophthalmus, aniridia***

Eye malformations can also occur and may effect vision. Some children may be born with **microphthalmos**, which is extremely small eyeballs. It is common in children who had congenital rubella and is associated with poor visual acuity and nystagmus. Two other eye malformations include **anophthalmus** (absence of eyes), or **aniridia** (partial or complete absence of the iris).

*Coloboma*

A lesion or defect in the eye, known as **coloboma** can occur when there is a cleft, notch, gap or fissure in the iris, ciliary body, choroid or optic nerve. This occurs as a failure of the cleft to close during early prenatal development (about 6 weeks after conception) which prevents formation of an intact, complete eyeball. If the retina or optic nerve is involved, there is usually a scotoma (blind spot) or field loss corresponding to the site of the defect (Apple & Rebb, 1991). Often the field loss is located in the upper fields of vision causing a person difficulty seeing low overhanging tree limbs, signs or cabinets (Jose, 1983). There may be a decrease in visual acuity, as well as such concomitant visual abnormalities as strabismus or nystagmus.

Colobomas may occur unassociated with other abnormalities or may occur in such conditions as Trisomy 13 and CHARGE association.

## *Disorders of the Visual Pathways*

The visual pathways of the optic nerve, optic tract and optic radiations may be affected and result in visual impairment.

***Atrophy of the optic nerve***

**Atrophy of the optic nerve** is the most common disorder of the visual pathways. It can be hereditary and/or can be caused by numerous diseases and disorders (e.g. retinitis pigmentosa, tumors, hydrocephalus, and head trauma). Central visual loss and field losses are often present with the visual loss typically being roughly proportional to the amount of nerve atrophy. Total blindness can result (Berkow, 1987).

***Congenital optic nerve hypoplasia***

Another optic nerve disorder which causes visual impairment is congenital **optic nerve hypoplasia (CONH)**. In this disorder there is incomplete development of the optic nerve. It causes variable degrees of visual impairment. It is often associated with neurological disorders and endocrine problems.

## *Disorders of the Visual Cortex*

Cortical visual impairment (also known as cortical blindness) is a term used to describe damage to the visual pathways or cortex of the brain. In these instances, the eye shows no pathology, however the brain is unable to process the incoming visual information. The resulting visual impairment may range from partial loss of visual acuity to blindness, depending on the exact location of the damage. Visual field defects may be present as well.

There are several causes of cortical visual impairment. Some of these include: closed head injury, drowning, prolonged convulsion, meningitis, and hypoxia resulting in brain damage. With some of these, visual improvement may occur over time. Hydrocephalus, which is not adequately treated with shunting, may also result in a visual loss. Some improvement in vision may occur after shunting, but this is not

always the case (Buncic, 1987). Sometimes cortical visual impairment occurs in children with retardation.

## *Disorders of Visual Functioning*

There are several disorders which may affect proper functioning of the eye in regard to: visual acuity, fields of vision, ocular motility, reflexive visual processes and color discrimination (McLaughlin & Lewis, 1986). These visual processes may be impaired from numerous causes and need careful assessment to determine proper function.

### *Visual acuity.*

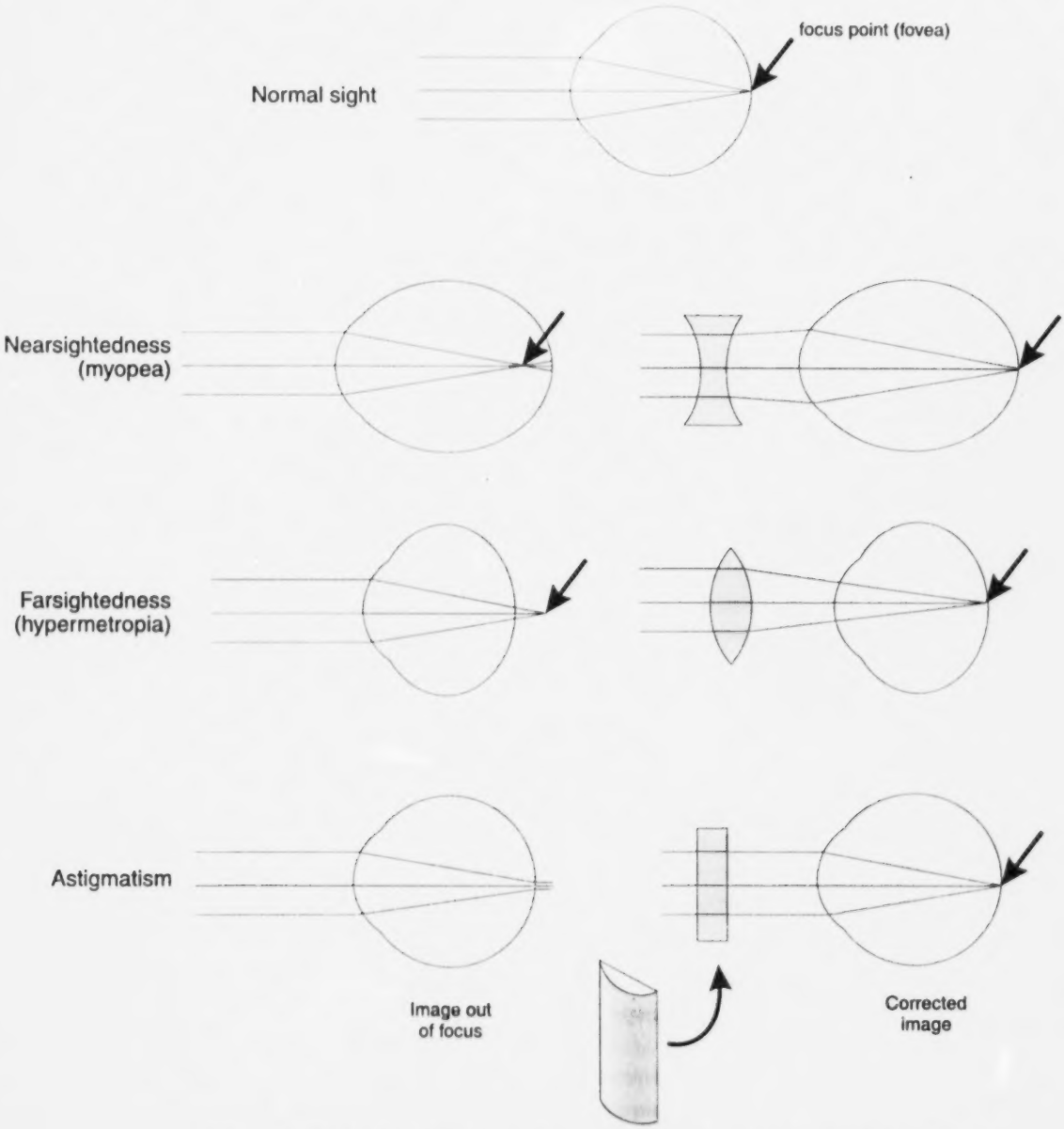
Visual acuity refers to how clear or sharp an image is in regard to forms or patterns (Cress, 1988). It is described in terms of near and far vision. Near vision is considered the ability to clearly perceive objects at about 14 inches from the eyes (Ward, 1986). When individuals can not clearly see near objects due to a active error, this is known as **hyperopia** (farsightedness). In hyperopia, the eye is either smaller than normal, or its active power is weaker than the normal system (Jose, 1983). When the light rays enter the eye, they do not properly focus on the retina. The light rays fall behind the retina, resulting in the ability to only see far objects clearly, but not near objects. A convex lens (in glasses or contacts) is needed to focus the light rays on the retina to allow for clear near vision. (see Figure 9).

Far vision describes how well someone sees objects or symbols at a distance. It is typically reported in ratios such as 20/20, 20/ 70, etc. Normal visual acuity is considered 20/20. The first numbers refers to how many feet the letters, symbols or objects are from the person. The second number refers to the size of the symbols which represent the distance a person with normal vision could read them. For example, a person with 20/70 vision sees at a distance of twenty feet what a person with unimpaired vision sees at a distance of 70 feet. Individuals with a active error affecting distance vision are considered to have **myopia** (nearsightedness). In myopia, the eyeball is either longer than normal or the eye has greater than normal active power. Due to either occurrence, the light rays focus in front of the retina causing difficulty seeing objects far away. A concave lens (in glasses or contacts) is needed to focus the light rays on the retina.

Another condition which may affect visual acuity is **astigmatism**. In this condition there is an unequal curvature of the cornea or lens. In this condition, light does not come to a single point of focus on the retina. Astigmatism results in blurred or distorted images by itself or in combination with farsightedness and nearsightedness. When the stigmatism is moderate or severe, cylindrical lenses are prescribed.

#### *Defects in visual fields*

**Defects in visual fields** is another type of visual impairment. Normal visual fields include areas of peripheral and central vision. Visual field defects or blind spots can result in peripheral vision losses, central vision losses or losses in specific quadrants (see Figure 10). Peripheral vision losses include losses in the outer portions of the visual field (e.g. retinitis pigmentosa). Peripheral field loss results in a reduced angle




If the eyeball is too long, images are focused in front of the retina (myopia). A concave lens deflects the rays, correcting the problem. If the eyeball is too short, the image focuses behind the retina and is again blurred (hyperpetropia). A conve lens corrects this.
In astigmatism, the eyeball is the correct size, but the cornea is misshapen. A cylindrical lens is required to compensate.

*Figure 9 Myopia, hyperopia, and stigmatism*

of vision, or limits how much a person can see at one time. Since the rods which assist in seeing in dim light are located in the periphery, a deficit in this area may be accompanied by loss of night vision. A person with a peripheral loss will find if difficult to see in dim light and travel independently at night.

Central vision loss refers to visual losses is the central field of vision. It is due to disorders affecting the macula portion of the retina (e.g. macular degeneration, or atypical retinitis pigmentosa). A person with a central vision loss may miss seeing academic material or objects in their path unless proper programming is in place.

A person may also have scotoma (blind spots) which affect the visual fields. Both central and peripheral vision may be affected with scotomas.

Specific visual field deficits also include hemianopsia (one half of the visual field in both eyes missing) (see Figure 10) and quadrant loss (one fourth of the visual field is missing). These occur more commonly due to a tumor along the visual pathways or brain trauma. This is also present in children with cerebral palsy.

*Disorders of ocular motility*

**Ocular motility** refers to the movement of the eye by any of the six muscles surrounding each eye (i.e., extraocular muscles). Difficulties in ocular motility may occur in individuals with facial paralysis, eye muscle imbalances, cranial nerve damage or other conditions which may result in diminished or loss of eye muscle movement.

*Strabismus*

Impairments in eye muscle movement can result in **strabismus** (which is when one or both eyes deviate from correct alignment). Types of strabismus are: esotropia (where one or both eyes turns in (i.e. nasally)), exotropia (where one or both eyes turn out (i.e. temporally)), and hypertropia where the eye deviates upward. When one eye deviates, **diplopia** (double vision) can occur. Often the brain will suppress one image so that only one visual image will be seen instead of double.

*Amblyopia*

The suppression of one image by the brain in individuals with strabismus is the leading cause of **amblyopia**. Amblyopia is a reduction of corrected central visual acuity in the absence of ophthalmoscopically visual abnormalities. It can also occur due to unequal active errors or other less common causes (Friendly, 1987). The suppression of images transmitted by one eye can lead to eventual blindness in the unused eye (Rosenthal, 1982). This can be avoided with appropriate intervention implemented at an early age.

Impairments in ocular motility may also result in difficulties with tracking, convergence, gaze shift and scanning.

*Nystagmus*

Another abnormal ocular movements is **nystagmus**. Nystagmus consists of involuntary, rhythmic eye movements, primarily in the horizontal plane. However, movement may be vertical, diagonal, or rotary and can be fast or slow. Drifting eye movements may be present and present as slow searching movements with no

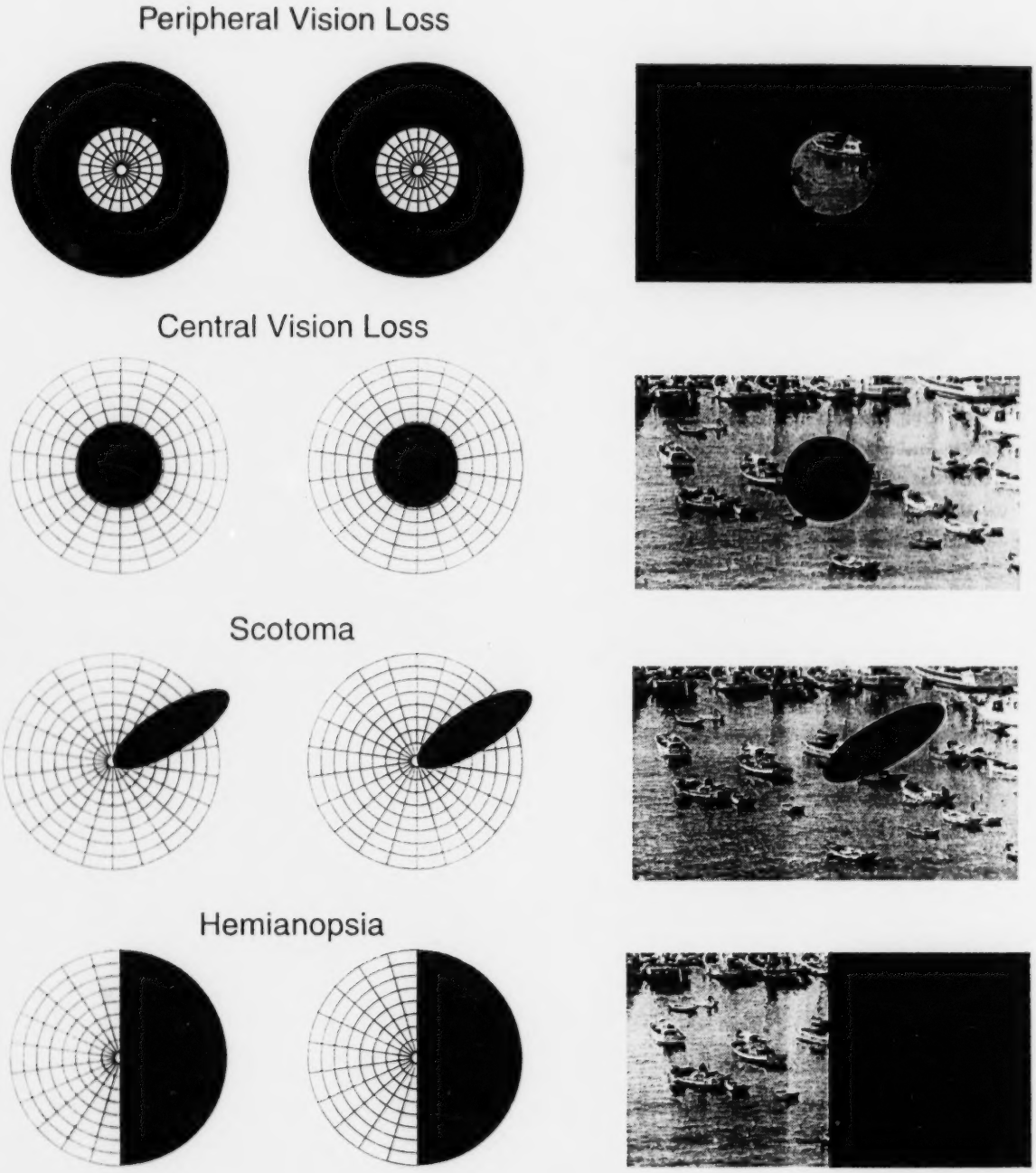



*Figure 10 Vision field loss*



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evidence of fixation. When nystagmus is present during the first year of life, it may be indicative of the presence of a bilateral vision loss. It can also be due to a neurological impairment (i.e. hydrocephalus). When nystagmus occurs later, the individual may have poor visual acuity in the affected eye, although binocular vision may be unimpaired. Nystagmus is usually associated with congenital visual abnormalities (Hoyt, 1987).

***Disorders of pupillary response and blink reflex***

The **pupillary response** and the **protective blink reflex** are two reflexive visual processes. The pupillary response is a change in the size of the pupil in response to light. In bright light, the pupil appears to constrict to allow less light into the eye. In dim light, the pupil is enlarged to allow more light into the eye. In some disorders (and under the effects of certain medications), the pupil may be more dilated or constricted than normal or may not change in response to changes in illumination.

The protective blink reflex refers to the ability of the eye to close when a threat to the eye is imminent (Cress, 1988). Assessment of this reflex assists in determining if the person has any functional vision. If the person has vision, but nonfunctioning reflexes, bright lights may be uncomfortable for some individuals whose pupils do not constrict and an increase risk of eye injury may be present when the blink reflex is absent.

***Disorders in color perception***

Some individuals may have difficulty perceiving color. Individuals who are **color blind** usually can not see certain colors due to missing or damaged cones (color receptors) in the eye. This is typically a sex-linked genetic abnormality and results from absence of color genes on the X chromosome. The most common type of color blindness are red-green blindness (in which red and green appear the same color), red blindness, and green blindness. Very rare is blue-yellow color blindness (Vaughan, Asbury, & Riordan-Eva, 1992).

The functional vision assessment will assist in determining how well the individual sees, as well as what adaptations are needed. Often environmental arrangements, such as controlling the amount of light, and presenting materials with textures or contrast will be helpful.

## *Disorders of Hearing*

There are several types of common hearing disorders classified by location of impairment. They can be divided into disorders of the outer ear (conductive loss), middle ear (conductive loss), outer and/or middle ear together with inner ear (mixed loss), inner ear and cochlear eighth cranial nerve (sensorineural loss), and central auditory mechanism (central loss) (see Figure 11).

### *Disorders of the Outer Ear: Conductive Loss*

When there is a disorder of the outer ear which affects hearing, it is classified as a conductive hearing loss. There are several types of conditions which result in

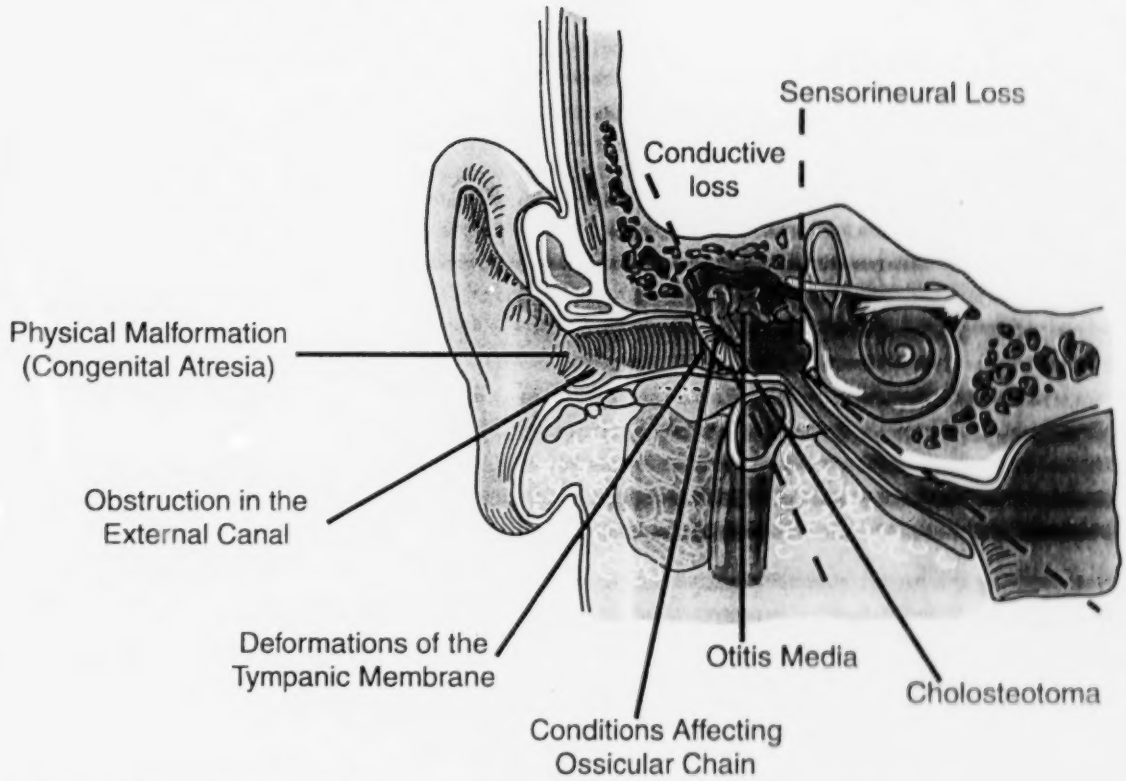


*Figure 11 Common disorders of the ear*

conductive hearing losses. There can be physical malformations such as **congenital atresia** (absence or closure of the external auditory canal) or obstruction in the external auditory canal from impacted cerumen (wax), foreign bodies, or a tumor. Infections such as external otitis (an infection of the skin of the external auditory canal, also known as swimmers ear) may also impede hearing.

The tympanic membrane (eardrum), bordering between the outer and middle ear, may become perforated due to an infection or a blow to the head. This results in a conductive loss as well.

## *Disorders of the Middle Ear: Conductive Loss*

### *Otitis media*

One of the most frequent causes of a conductive hearing loss is **otitis media**. Otitis media is an inflammation of the middle ear that is frequently caused by a bacterial or viral infection. Often otitis media is accompanied by fluid in the middle ear which restricts movement of the tympanic membrane. This restriction of movement can result in a moderate hearing loss and possible rupture of the tympanic membrane. Prompt treatment with antibiotics and much less frequently, Myringotomy (lancing of the eardrum) should clear the infection and allow return of normal hearing. Another form of otitis media can occur (serous otitis media) in which there is no

infection, but negative pressure occurs in the middle ear, secondary to the poor eustachian tube formation with resultant accumulation of fluid in the middle ear cavity.This can also result in a conductive hearing loss that may require myringotomy and possible insertion of a ventilation tube into the tympanic membrane.

*Cholesteatoma*

There are several other abnormalities of the middle ear which can cause hearing impairment. **Cholesteatoma** is a congenital or acquired benign skin-like mass which can occur in the middle ear and the other areas of the temporal bone. It typically develops as a complication of chronic or recurrent otitis media. Perforation of the tympanic membrane often occurs. One danger of this condition is the possible erosion of auditory or cranial structures, such as the destruction of the middle ear bone. Depending on the location of the cholesteatoma, there may be no hearing loss, progressive conductive hearing loss, or sensorineural hearing loss. Recurrent drainage from the ear (otorrhea) is common. Complications of a cholesteatoma such as menningitis, from abscess and facial paralysis are uncommon today but still occur.

*Conditions affecting the ossicular chain*

**Conditions affecting the ossicular chain (middle ear bones)** include discontinuity of the ossicular chain and fixation of one or more bones. Discontinuity of the ossicular chain refers to disruption of the connections between the malleus, incus and stapes. This may occur from congenital defects, head trauma or middle ear disease. Fixation of a middle ear bone may be a congenital or acquired condition in which there is an unusually firm attachment between one or more bones and other portions of the middle ear (e.g. malleus fixation to the roof of the middle ear). Stapes fixation to the rear of the oval window is usually caused by a condition called otosclerosis. These conditions generally produce a conductive hearing loss and frequently can be improved with surgery.

## *Disorders of the Inner Ear & VIII Cranial Nerve: Sensorineural Loss*

A hearing loss due to a dysfunction of the inner ear on the pathway from the inner ear to the brainstem is referred to as a sensorineural loss. In this type of hearing loss, sound reaches the inner ear, but is not completely transmitted to the brain. Typically the individual can not hear the high frequencies; the frequencies needed to understand speech. Most babies born with a hearing loss have a sensorineural loss. This is the case in such conditions as Usher's syndrome and congenital infections which result in hearing impairment. However a sensorineural loss may be acquired as well from such causes as ototoxic drugs, trauma, and infections (meningitis) (Ludman, 1988).

## *Disorders of Outer, Middle, Inner Ear: Mixed Loss*

In some conditions and syndromes, a hearing loss is present in which there is both are both conductive and sensorineural losses. This is referred to as a mixed loss.

### *Disorders of Central Auditory System: Central loss*

A central hearing loss occurs if there are abnormalities in the auditory cortex or the pathways going from the brainstem to the auditory cortex. This may be caused by a brain tumor, vascular changes in the brain or congenital or acquired brain damage. In central deafness, the mechanics of the ear are working correctly, but the individual can not interpret the auditory messages due to damage in the area of the brain which receives the transmissions (Beadle, 1982).

### *Disorders of Functional Hearing*

As with visual impairments, a careful assessment of functional hearing is necessary to accurately determine what the individual can hear. A functional description will inform the teacher, service provider or parent how well and in what situations the individual can hear best. Some students will benefit from use of environmental adaptations and auditory aides.

Section II

# *Causes of Deaf-Blindness*

There are several conditions and syndromes which result in both visual and auditory impairments. The various causes of deaf-blindness will be discussed in this section, emphasizing the characteristics of the conditions and the specific auditory and visual impairments which can occur. Some of the common visual and auditory disorders which occur in the described disorders and have been described in Chapter 3. The reader may want to refer to them for a more detailed explanation.

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## Chapter 4

# *Hereditary Syndromes and Disorders*

There are many different syndromes and disorders which result in visual and auditory impairments. This chapter will present a basic overview of these, stressing possible visual and auditory impairments. These various syndromes and disorders have resulted in children having deaf-blindness.

Although it may be surprising that these two sensory organs would both be impaired, this can be explained by their similar embryonic development. Both eyes and ears develop primarily during the first twelve weeks of pregnancy. Also, both the eye and ear originate from some of the same type of embryonic cells and tissue and have several anatomical similarities (Regenbogen & Coscas, 1985). Because of these similarities, various diseases and conditions result in damage to both organs.

## *Down Syndrome*

Down syndrome, also known as Trisomy 21, is one of the most common chromosomal abnormalities. In this condition, there is an extra chromosome (or extra part of a chromosome) in the cells of the body. This results in several distinct physical characteristics and abnormalities.

Three primary causes of Down syndrome have been identified. In most cases, Down syndrome results from nondisjunction which is a failure of the chromosome 21 to separate. Another cause known as translocation, is for an extra chromosome 21 to be attached to another chromosome. The smallest percent of individuals with Down syndrome have Mosaicism where an abnormal separation of chromosome 21 occurs sometime after conception. Only some of the cells in mosaic Down would have an abnormal number of chromosomes. In this type of Down syndrome, the child may not have all the typical characteristics of Down syndrome. This would depend upon the percentage of body cells with the extra chromosome (Blackman, 1990).

There are several typical physical characteristics in individuals with Down syndrome. Some of these are: a small stature, decreased muscle tone (hypotonia), hyperflexibility of the joints, flattened bridge of nose, small head (microcephaly), protruding tongue, wide gap between first and second toe, flat feet, and short, and broad hands with single palmar crease (simian crease). Children with Down syndrome also are usually mentally retarded, although some with mosaic Down syndrome have been found to have normal intelligence (Berkow, 1987). Congenital heart defects and blockage of the small intestine (duodenal atresia) are often present.

Some children with Down syndrome will have instability between the first two cervical vertebra (atlantaoaxial subluxation) (Blackman, 1990).

### *Visual and Auditory Impairment*

Children with Down syndrome often have eye abnormalities. When a child is born with Down syndrome, Brushfield spots (gray to white spots around the periphery of the iris) are often present. This usually disappears during the first year of life. The eyes are typically slanted with extra skin folds at the inner corners of the eye (epicanthal folds). Inflammation of the eyelids (blepharitis) may also occur. Problems in visual acuity (nearsightedness and far-sightedness) and strabismus (cross-eyes) are often present (Diamond, 1982). Keratoconus (cone shaped cornea) may also occur (Lucas, 1989) as well as cataracts (Martyn & DiGeorge, 1987).

Children with Down syndrome are often at risk of having hearing impairments. Difficulties in auditory perception have been found (MacMillan,1977) and mild to moderate hearing loss may be present (Blackman, 1990). Conductive hearing losses may occur from recurrent and persistent middle ear infections.

### *Outcomes*

Vision and hearing problems may remain present.Major medical problems such as congenital heart defects and blockage of the small intestine (duodenal atresia) are typically medically and surgically managed in infancy.

## *Trisomy 13*

Trisomy 13, also known at Patau's syndrome, is an autosomal aberration in which there are three number 13 chromosomes in a cell instead of a pair. This syndrome is characterized by severe physical abnormalities with many individuals dying in infancy.

Some of the more frequent abnormalities include a small head (microcephaly), gross anatomic defects of the brain (such as holoprosencephaly or failure of the forebrain to divide properly), cleft lip and palate, and congenital heart abnormalities. A Simian crease and extra fingers or toes are common (Berkow, 1987). Typically the child is severely mentally retarded.

### *Visual and Auditory Impairment*

Children with Trisomy 13 frequently have microphthalmia (abnormally small eyes), colobomas (fissures) of the iris and retinal dysplasia (abnormal development of retinal tissue (Berkow, 1987). Cataracts may also be present (Martyn & DiGeorge, 1987). This results in varying degrees of visual impairment.

Hearing impairment and deafness may be present.

## Usher's Syndrome

Usher's syndrome is the leading cause of combined deaf-blindness after childhood. It is autosomal recessive and consists of a combined congenital hearing loss and slowly progressive retinitis pigmentosa. This syndrome has been divided into four types, with type III and IV being very rare. The most common type, Type I, consists of profound congenital deafness with retinitis pigmentosa. There is no mental or neurological impairment. In Type II, there is a moderate-severe hearing loss and retinitis pigmentosa. Normal intelligence is present. In Type III, complete congenital deafness combined with retinitis pigmentosa occurs. Mild motor incoordination is typically present. (See Hallgren syndrome). Type IV is similar to Type I, but mental retardation is present (Regenbogen & Coscas, 1985).

### *Visual and Auditory Impairment*

Retinitis Pigmentosa usually begins around adolescence/ early adulthood. The first symptom, night blindness, may be present earlier and result in difficulty seeing in dim light. As retinitis pigmentosa progresses, visual loss in the peripheral fields begins with eventual tunnel vision. Blindness may not occur until middle or late adult life.

The congenital hearing loss is typically sensorineural with a severe to moderate loss in both ears. Usually the loss is present in the higher frequencies.

## Alstrom Syndrome

Alstrom syndrome is a autosomal recessive disorder in which affected children usually have obesity (very fat), diabetes mellitus, profound blindness and progressive deafness. Skeletal abnormalities and chronic renal impairment may also occur. Individuals with Alstrom syndrome usually have normal intelligence.

### *Visual and Auditory Impairment*

The first signs of eye disease begin with the presence of nystagmus and the infant/child showing sensitivity to light. Blindness occurs from an atypical retinitis pigmentosa in which there is first a loss of central vision. Vision loss progressively worsens and by age seven, very little vision remains. Mild to moderate cataracts develop in the teens for the majority of individuals with this syndrome. Glaucoma and dislocated lens have been reported as secondary complications (Regenbogen & Coscas, 1985).

A mild sensorineural hearing loss usually occurs in both ears around seven to ten years of age. This progresses to a moderate to severe hearing loss in the second and third decades of life (Regenbogen & Coscas, 1985).

# CHARGE Association

CHARGE association refers to the presence of several concominent malformations. The mnemonic stands for: coloboma, heart disease, atresia choanae, retarded growth, genital hypoplasia and ear anomalies/deafness. In order to identify an individual as having CHARGE association, four of these abnormalities must be present. Some individuals suggest that there may be a less severe form of this syndrome.

Coloboma is a slit or groove in the iris, ciliary body, choroid or retina. It is due to a failure of the optic cleft to completely close at about six weeks of fetal life. It may range from a slit or groove in the iris which causes no visual impairment to a missing eye (anophthalmos).

In CHARGE assoication, heart disease referes to several possible defects in the heart which are present from birth. (Some of these include ventricular septal defects, patent ductus arteriosus, tetralogy of Fallot and bicuspid aortic valve.)

Choanal atresia is a closure between the nasal cavity and the passageway for air from the nasal cavity to the windpipe (nasopharynx). If it is unilateral (one sided), symptoms are minor. However, if it bilateral (both sides), the infant will show severe respiratory distress and most infants will die from asphyxiation unless corrected.

Other abnormalities are often present in individuals identified as having CHARGE association. These include mental retardation, small head (microcephaly), cleft lip and palate, and facial nerve palsy. Central nervous system malformations have been present as well (Lin, Siebert, & Graham, 1990). Feeding difficulties may be present. Abnormalities of the genitourinary system have occurred as well as malformations of the vertebrae and ribs.

## *Visual and Auditory problems*

As previously mentioned, coloboma is the typical eye abnormality. It may involve one or both eyes. The effect on the person's vision may be minimal or may result in visual field losses (often occurring in the upper field of vision) as well as decreases in visual acuity. Total loss of vision will be present if anophthalmos occurs.

Other eye abnormalities may be present in CHARGE Association. These include microphthalmus (small eyes), optic nerve hypoplasia (defective development of optic nerve), cataract, retinal detachment, nystagmus and disorders of refraction and ocular movement (Russel-Eggitt, Blake, Taylor, & Wyre, 1990).

The mixed hearing loss often results from combination of sensorineural loss and structural deformities in the outer ear. External auditory abnormalities range from an absence of the external aúditory canal opening to deformities of the pinna. Chronic otitis media (middle ear infection) may be present. Hearing loss ranges form mild to profound loss (Regenbogen & Coscas, 1985).

## Cockayne Syndrome

Cockayne syndrome is an autosomal recessive disorder which consists of dwarfism, mental retardation, retinitis pigmentosa with optic atrophy and deafness. Individual faces are usually thin with prominent noses and large ears. The face usually has the appearance of an old man/woman (progeria). Humpback (kyphosis), microcephaly (small head), enlarged liver and spleen, growth deficiency, unsteady gait and tremors may also be present.

There may possibly be two forms of the syndrome. In one form, the symptoms appear after birth and result in death at five or six years. In the second type, symptoms are not present until the second year of life and the syndrome slowly progresses for twenty years (Regenbogen & Coscas, 1985).

### *Visual and Auditory Impairments*

Individuals with Cockayne syndrome have retinitis pigmentosa with optic atrophy. This results in night blindness, peripheral field deficits and eventually blindness occurring in the second decade of life. Other eye abnormalities include enophthalmos (sunken eyes), cataracts, nystagmus and sensitivity to light (Apple & Rabb, 1991).

Hearing is usually normal at birth, but a progressive sensorineural loss becomes present. It is usually in both ears and results in a moderate to severe hearing loss (Regenbogen & Coscas, 1985).

## Crouzon

Crouzon syndrome, also known as craniofacial dysostosis involves skull and facial deformities, with visual and auditory impairments often being present. As the infants head begins to grow, the skull expands in abnormal directions resulting in various facial and skull deformities. An increase in intracranial pressure may develop as the brain growth resulting in headaches, seizures and injury to the nervous system. Mental retardation may be present (Regenbogen & Coscas, 1985).

### *Visual and Auditory Impairments*

There are several possible eye abnormalities with Crouzon syndrome. Individuals often have exophthalmos (abnormal protrusion of the eyeball) and an abnormal width between the eyes. The exophthalmos may lead to an inability to completely close the eyelids, inflammation of the cornea and in extreme cases, dislocation of the eyeball.

Other eye abnormalities involve strabismus and optic atrophy (Regenbogen & Coscas, 1985). In strabismus, the affected eye deviates from the line of vision. In this syndrome, the eye often deviates outward. In optic atrophy, there is a wasting away of the optic nerve in which visual impairment may occur around six or seven years of age. The vision impairment may be mild, involving an upper visual field deficit,

or more severe. Cataracts and retinal detachments may also occur with this syndrome.

When a hearing impairment is present, it is usually nonprogressive with a conductive or mixed loss (although sole sensorineural losses have occasionally been present). The conductive loss is usually due to malformation of the three bones in the middle ear or due to the external auditory canal being narrowed or closed. Other ear abnormalities include the ears being lower set and the pinna being large (Regenbogen & Coscas, 1985).

### *Outcome*

Surgical intervention may be needed during infancy to provide space for the growing brain and prevent further injury. When the individual reaches eight, if there has been no increase in intracranial pressure, vision and mental development are usually good.

## *Goldenhar Syndrome*

Goldenhar syndrome (also known a oculo-auriculovertebral dysplasia) consists of several defects found at birth. There are skinlike cysts on the eyeball (epibulbar dermoids), appendages in front of the ear and ear malformations. Usually these defects only occur on one side. Other abnormalities to the face, teeth and mouth area may be present (e.g. receding chin, small jaw, and cleft lip and palate). Mild spinal abnormalities have been found in about half of individuals with this syndrome. Congenital heart disease and renal abnormalities may be present as well (Regenbogen & Coscas, 1985).

### *Visual/Auditory Impairments*

The eye has several physical abnormalities which may impair vision. The skin like cysts (epibulbar dermoids), which is the most frequent feature of this syndrome, may cause irregular stigmatism. Coloboma of the eyelid, iris or choroid may occur. Cataracts, nystagmus, strabismus, and retinal detachment have also been present, adversely affecting vision. Central visual pathway abnormalities may also occur, further impairing vision.

Physical malformation of the ear in the form of appendages near the ear or malformed outer ear is common in this syndrome. Conductive hearing loss may occur due to the external ear canal being absent or narrowed. Abnormalities in the middle ear may also be responsible for the conductive loss. Sensorineural hearing loss may occur from abnormalities in the inner ear. A mixed loss may be present as well. Hearing loss is usually only in one ear.

## Hallgren Syndrome

Hallgren syndrome is an autosomal recessive disorder which has been considered as a third type of Usher's syndrome. It consists of ataxia (muscular incoordination), congenital deafness and retinitis pigmentosa. Ataxia is usually mild and presents itself as a swinging gait. Children will usually walk late because of it. Mental retardation has been assoicated with some individuls with this syndrome. Less common symptoms include skeletal abnormalities (club foot, hunchback) and seizures (Regenbogen & Coscas, 1985).

### Visual and Auditory Impairments

The primary visual problem in Hallgren syndrome is retinitis pigmentosa. Night blindness is usually present by preschool age and a diganosis of retinitis pigmentosa occurs between seven and fiteen years of age. The retinitis pigmentosa found in individuals with Hallgren syndrome usually has a better prognosis than typical retinitis pigmentosa. There is usually a moderate rate of progression of the condition with blindness occurring between 41 and 70 years of age (Regenbogen & Coscas, 1985).

The majority of individuals with this syndrome have total or almost total sensorineural deafness of both ears. Other individuals do have enough hearing to understand words. The hearing loss is not progessive.

## Kearns-Sayre Syndrome

Kearns-Sayre Syndrome is an autosomal syndrome in which there is a defect in one of the (mitochondrial respiratory chain) enzymes which leads to structural abnormalities of the energy producing element of cells (mitochondria) (Gota, Itami, Kajii, Tochimaru, Endo & Horai, 1990). This syndrome is characterized by a progressive external ophthalmoplegia (ocular muscle paralysis), atypical retinitis pigmentosa and sensorineural hearing loss. Heart problems often develop later in this syndrome and range from mild abnormalities (e.g., bundle branch blocks) to serious blocks (e.g., AV heart block) which may require a pacemaker (Regenbogen & Coscas, 1985).

Several other symptoms may be present. Cerebellar ataxia (muscular incoordination) can occur and it is often mild at first. However, it can progressively worsen, adversely affecting movement. Growth may be impaired in children who have this syndrome before puberty. Mental retardation may be present. Weakness in the face, neck and extremities may also occur.

Three forms of the syndrome have been identified. There is an infantile form which tends to have a severe and rapid course. There is also a juvenile form. The adult form is usually less severe and progresses slowly.

### *Visual and Auditory Impairment*

The first visual impairment is the external ophthalmoplegia. This becomes progressively worse over months or years until complete paralysis of the ocular muscles occur.

The atypical retinitis pigmentosa begins soon after the presence of external ophthalmoplegia and is usually in both eyes. It can cause a wide range of visual impairments. In many cases the abnormal retinitis pigmentosa may cause only minor to no loss of visual acuity. However, in some cases the retinitis pigmentosa is more typical and cause visual field deficits. This may take the form of some peripheral loss of vision, central scotoma (blind spot in the center of vision), ring scotoma or blind spots in other areas. Some individuals can compensate for the blind spots by tilting their heads backwards. Other eye abnormalities may include pupil abnormalities and cataracts (Regenbogen & Coscas, 1985).

In terms of auditory problems, sensorineural hearing loss has been found in about half of the individuals with this syndrome (Regenbogen & Coscas, 1985). The hearing loss is greater in the higher frequencies, but can range overall from mild to profound. The sensorineural loss may be progressive and may begin between three and ten years of age.

## *Mucopolysaccharidosis*

The mucopolysaccharidosis (MPS) are inborn errors of mucopolysaccharides metabolism in which there is a defect or deficiency in (lysosomal) enzymes that degrade certain mucopolysaccharides. The incompletely degraded mucopolysaccharides accumulate in several organ systems and lead to progressive abnormalities. Five types of MPS have both visual and hearing abnormalities and most are autosomal recessive. The five types include: Hurler (MPS-1), Scheie (MPS I-S), Hunter (MPS II), Morquio (MPS IV), Maroteaux-Lamy (MPS VI).

### *Hurler Syndrome (MPS-I H)*

The major characteristics of Hurler's syndrome consist of dwarfism, large head, nasal discharge, skeletal abnormalities, enlarged liver and spleen and ape-like posture. The facial features have led to the name of "gargoylism" to refer to this entire syndrome. The progressive mucopolysaccharides deposits in the windpipe (trachea) can lead to airway obstruction if not treated (Adachi & Chole, 1990). The full features of the syndrome develop between one and two years of age. After two years, mental development deteriorates and often severe mental retardation is present. Neurological symptoms appear as degeneration occurs. These symptoms include seizures, spastic paraplegia, nystagmus and ataxia (muscular incoordination) (Regenbogen & Coscas, 1985).

### *Visual and Auditory Impairment*

The most common ocular feature of Hurler's syndrome is corneal clouding which often appears at three year of age and progresses slowly, affecting visual acuity. Visual acuity may be severely affected as the individual reaches 30 years of age or older. Occasionally the eyes may have painful episodes with the sensation of a foreign body begin in the eye as well as photophobia (avoidance of light). Other abnormalities include atypical regional pigmentary degeneration and optic atrophy (Collins, Traboulsi, & Maumence, 1990).

Most individuals with Hurlers have some degree of mild mixed hearing loss which is progressive. The conductive loss may be due to repeated otitis media (middle ear infections) and deformity of the ossicles (three bones in the middle ear). Deformity of the inner ear may also exist resulting in sensorineural loss (Regenbogen & Coscas, 1985).

### *Scheie Syndrome (MPS-I S)*

Scheie syndrome is caused by the same enzyme defect as Hurler's syndrome, but it is less severe and individuals with this syndrome are of normal intelligence. Some characteristics which individuals with Scheie may have is corneal clouding, skeletal abnormalities (hand and face deformity), broad faces (but not gargoylism), and heart abnormalities. Respiratory infections are common (Keith, Scully & Weidman, 1990).

### *Visual and Auditory Impairments*

For individuals with Scheie syndrome, slowly progressive corneal clouding occurs which interferes with vision. The corneal clouding may be present at birth or not until the second decade of life. Diminished vision in bright light occurs with decrease in field of vision. Glaucoma may also be present. In some cases there is atypical retinitis pigmentosa (Apple & Rabb, 1991).

There is typically a mixed hearing loss which is progressive. It is usually present in middle age and rarely develop into a total loss (Regenbogen & Coscas, 1985).

### *Hunter Syndrome (MPS-II)*

Two forms of Hunter's syndrome occur with differing outcomes. The common severe form (MPS II A) results in mental deterioration and death, usually prior to the fifteenth birthday. The other form (MPS II B) is milder and the individual usually has normal (or near normal) intelligence with a normal life expectancy.

Many of the symptoms of MPS II are similar to MPS I, but milder. During the first year of life, respiratory infections, noisy breathing and hernia may be present. Not until two years of age do the more prominent features occur. These include: growth retardation, joint stiffness, enlarged liver and spleen and protruding abdomen. Two to six year old boys are typically hyperkinetic. After five to six years of age, physical and mental abilities deteriorate. The individual has night blindness, mixed hearing loss, dwarfism and gargoyle-like features. Complications include heart disease,

mucoid diarrhea, upper airway obstruction and hip disease (Regenbogen & Coscas, 1985).

### *Visual and Auditory Impairment*

Optic atrophy and atypical retinitis pigmentosa are often present in individuals with Hunter's syndrome. Severe night blindness is often present, interfering with vision in dim light. Other eye abnormalities include buphthalmos (infantile glaucoma in which there is an enlargement of the eye), abnormal width between the two eyes, glaucoma and exophthalmus (protrusion of the eyeball). Vision loss and blindness may occur (Regenbogen & Coscas, 1985).

A progressive hearing loss is usually present. It may be mixed or sensorineural. Recurrent otitis media may also occur.

## *Morquio Syndrome (MPS IV)*

This form of mucopolysaccharidosis disease may be present in a severe form (MPS IV A) or a mild form (MPS IV S). The main features consist of dwarfism, prominent lower face, thin enamel on the teeth, knock knees and joint laxity. A lack of endurance may occur about 4 to 6 years of age with increased difficulty walking. There is a tendency for respiratory infections. Intelligence is usually normal. Some additional abnormalities include: heart valve defects (aortic regurgitation) and enlargement of liver and spleen (Regenbogen & Coscas, 1985).

### *Visual and Auditory Impairment*

Corneal clouding occurs in this syndrome around ten years of age. However, this cloudiness is milder than other forms of MPS resulting in only slightly impaired visual acuity.

Hearing impairment begins in adolescence and progresses. It is usually a conductive loss, but becomes mixed as the person ages. The mixed loss is usually bilateral with a mild-moderate loss in all frequencies. An ossicular chain (three bones in the middle ear) deformity may cause the conductive hearing loss (Regenbogen & Coscas, 1985).

## *Maroteaux-Lamy Syndrome (MPH VI)*

Maroteaux-Lamy Syndrome is another mucopolysaccharide defect which resembles Hurler syndrome. There are three forms: severe, intermediate and mild. General characteristics include growth retardation resulting in short stature and severe disabilities humpback, flared rib cage, and breastbone protrusion. Deformities of the knees, hips, face and hand may occur. Enlarged liver and heart abnormalities may be present. With the milder form of this syndrome, gross skeletal deformities and cataracts are absent. In all forms of Maroteaux-Lamy syndrome, individuals are of normal intelligence (Regenbogen & Coscas, 1985).

### *Visual and Auditory Impairment*

Bilateral corneal clouding also occurs in this MPS syndrome and is progressive. As the corneal clouding advances, visual acuity may be severely impaired. Optic atrophy may occur.

Conductive, sensorineural and mixed hearing losses in both ears occur (Regenbogen & Coscas, 1985).

## *Refsum Syndrome*

Refsum syndrome is an autosomal recessive syndrome which affects the nervous system, eye, ear, heart and skin and is progressive. The major symptoms are chronic peripheral polyneuropathy, cerebellar ataxia, retinitis pigmentosa and progressive deafness. The neuropathy usually affects the feet and legs resulting in motor weakness and wasting away of muscles (muscle atrophy). A loss of deep sensation, superficial sensation to pain and parathesis may occur. In ataxia, there is an unsteadiness of gait.

Other symptoms include cardiac abnormalities (enlarged left ventricle of the heart, fast heart rate and irregular rhythms) and skeletal malformations. Age of onset varies from child to adult life. Sudden exacerbations and remissions may occur. Sudden, unexpected death has occurred in some cases (Regenbogen & Coscas, 1985).

### *Visual and Auditory Impairment*

Retinitis pigmentosa is the primary visual abnormality found in Refsum syndrome. Night blindness is usually the first symptom in childhood. A loss in peripheral vision occurs usually followed by concentric ring scotomas. Eventually only tunnel vision remains. Congenital cataract and nystagmus may also occur.

A sensorineural hearing loss begins in the second decade of life with the higher frequencies especially being affected. Progression may be slow or sudden. A complete loss may result (Regenbogen & Coscas, 1985).

## *Turner Syndrome*

Turner syndrome is one of the most common chromosomal abnormalities, in which there is a missing (or partially missing) sex chromosome. Due to this, it is also called the XO syndrome. Individuals are typically short in stature with height under five feet and there is usually a failure to develop secondary sexual traits during puberty. About half of those with this syndrome will have a webbing of the neck and peculiar "heart-shaped" faces. Other symptoms include low neck hairline, high palate, dental malocclusion, and congenital heart disease. Other additional abnormalities may include skeletal deformities, high blood pressure, and renal and urinary abnormalities. Also, poor visual memory, deficits in spatial ability and poor motor coordination may be present (Regenbogen & Coscas, 1985).

### *Visual and Auditory Impairments*

Although eye abnormalities are not common in Turner's syndrome, eye abnormalities have been found. Congenital epicanthus (fold of skin over eye), strabismus, and ptosis (drooping of eyelid) have been found to occur. Other eye abnormalities have been occasionally found. These include strabismus, cataracts, farsightedness, amblyopia, and color blindness.

Hearing abnormalities have been found in Turner syndrome but not frequently. Conductive, sensorineural and mixed hearing losses have all been present. Conductive losses may occur from outer and middle ear abnormality. Recurrent otitis media (middle ear infections) are very common and often occur in early childhood (Sculerati, Ledesma-Medina, Finegold & Stool, 1990). When conductive loss occurs, it is often moderate with more difficulty hearing in the higher frequencies. When sensorineural loss occurs, a particular pattern of the hearing loss is found on the audiogram with a symmetrical dip in the middle frequency range. (The maximum dip is between 500 and 2000 HZ with a loss of 20 - 70 Db.) Hearing loss is not progressive (Regenbogen & Coscas, 1985).

## *Waardenburg Syndrome*

Waardenburg syndrome is usually an autosomal dominant mutation producing a range of characteristics. Major characteristics include, hypopigmentation, deafness, optic abnormalities, alterations of the skeletal system (especially a wide distance between the eyes), dystopia canthorum medialis (malposition of the eyelids) and a white forelock or early graying of the hair (Asher, Morell & Friedman, 1991).

Three types of Waardenburg syndrome exist. Waardenburg syndrome type 1 (WS-1) occurs the most frequently and has the characteristic facial abnormalities. Type 2 is more associated with deafness. Type 3 is the most severe form with many musculo-skeletal abnormalities in the face and arms.

### *Visual and Auditory Impairments*

The cardinal sign of Type 1 Waardenburg is the increased distance between the eyes, but visual acuity is usually normal. Abnormal coloration of the iris, drooping of the eyelid and cataracts may also be present and affect vision.

Sensorineural deafness often occurs in this syndrome and it ranges in severity. Three distinct patterns of hearing loss are usually present. The first pattern consists of almost total deafness with slight residual hearing present in the low frequencies. The second type is severe deafness in the low frequencies, but normal in 6000-8000Hz range. The third type is unilateral (one sided) moderate hearing loss. Hearing loss may be progressive (Newton, 1989: Regenbogen & Coscas, 1985).

### *Other Syndromes*

For a listing of other syndromes associated with deaf-blindness, See Table 2.

| Other Syndromes Associated with Deaf-Blindness | |
|---|---|
| Alport | Marshall |
| Apert | Moebius |
| Bardet-Biedel | Norrie |
| Cogan | Nyssen-van Bogaert |
| Diallinas-Amalric | Pendred |
| DIDMOAD | Rosenberg-Chutorian |
| EEC | Sarcoidosis |
| Eldridge | Small |
| FOAR | Spranger-Wiedemann |
| Garcin | Strickler |
| Gradenigo | Strachnan |
| Harboyan | Vogt-Koyanagi-Harada |
| IVIC | Wegener Granulomatosis |
| Kniest Dysplagia | Wildervanck |
| LADD | Ziprkowski-Margolis |

*Table 2 Other syndromes associated with deaf-blindness*

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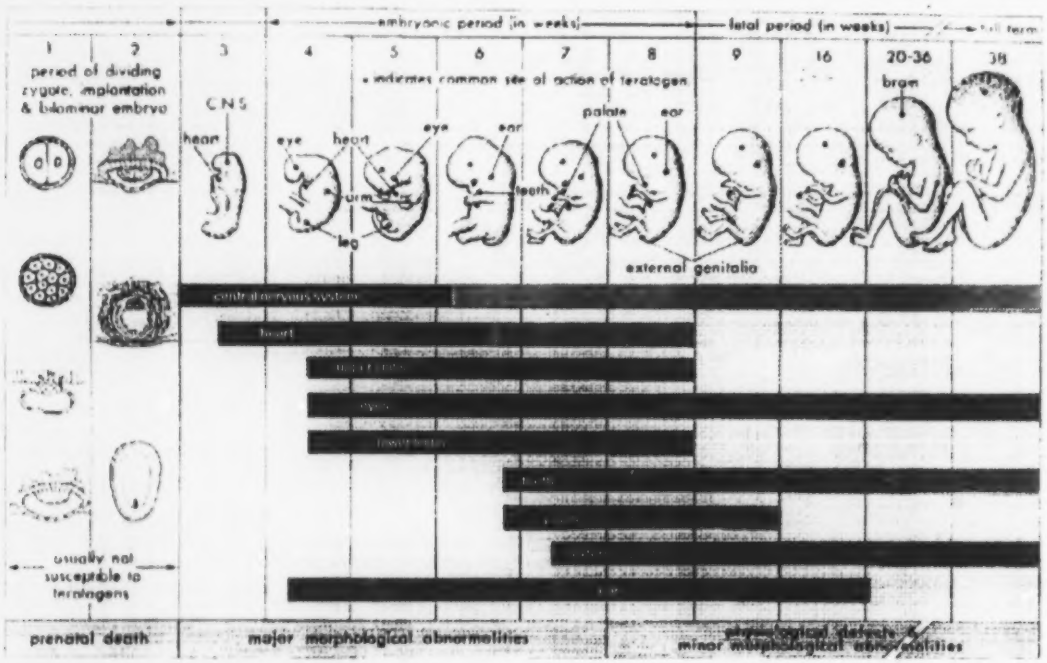
## Chapter 5

# *Congenital Infections and Teratogens*

Birth defects may occur when the developing fetus has been exposed to teratogenic agents, such as certain congenital infections, medications, illegal drugs, maternal illness or environmental chemicals. Initially, the mother acquires the infection or takes the teratogenic drug and then it is transmitted to the fetus. The extent of impairment to the developing fetus ranges from severe disabilities to no disabilities. This chapter will provide information on the general implications of congenital infections and other teratogens which can specifically affect vision and hearing.

The extent of impairment caused by a congenital infection or teratogen depends upon several factors. These include: the genetic composition of the fertilized egg, environmental and genetic factors in the mother, the type of infection or teratogen, the dosage of the medication, drug or chemical and the timing of exposure. (Schor, 1990). Certain times during the growth of the fetus are associated with greater risk to the developing organs and the visual and auditory systems (see Figure 12). For the eyes, an infection or teratogen could result in major structural abnormalities from the fourth week to the eighth week of intrauterine life, with minor abnormalities possible from the eight week to full term. For the ears, an infection or teratogen could result in major structural abnormalities from the fourth week to the ninth week, with minor abnormalities occurring from the ninth week to about the twentieth week.

Schematic illustration of the sensitive or critical periods in human development. The dark band denotes highly sensitive periods, the light band indicates stages that are less sensitive to teratogens. Note that each organ or structure has a critical period during which its development may be deranged and that physiological defects, functional disturbances, and minor morphological changes are likely to result from disturbances during the fetal period. Severe mental retardation may result from exposure of the developing human to high levels of radiation during the 8 to 16 week period.




**Source:** Reprinted from *Before We Are Born: Basic Embryology and Birth Defects*, 2nd ed., by K.L. Moore, with permission of W.B. Saunders Company © 1993.

*Figure 12 Fetal development*

## *Congenital Infections*

A group of the most common congenital infections resulting in birth defects are referred to by the mnemonic "STORCH". This stands for: Syphilis, Toxoplasmosis, Other, Rubella, Cytomegalovirus, and Herpes. Most infections which the mother acquires during pregnancy rarely result in any serious fetal infection. However, a STORCH infection may affect or damage the placenta or directly injure fetal organs. The extent of vision and hearing loss as well as other defects depend on the type of infection and the trimester in which the fetus was infected. Infections which occur early in pregnancy are more likely to result in more serious birth defects (Anderson, Bale, Blackman, & Murph, 1986).

With congenital infections, there is not only possible damage to the ears and eyes, but other common abnormalities often occur. These other abnormalities are summarized in Table 3. Similar complications to these infections are also found. Some of thee complications include mental retardation, shortened life span, poor

body growth, motor abnormalities, and glandular disturbances (e.g. thyroid and diabetes). For a better understanding of each of these congenital infections and their effect on vision and hearing, each infection will be described.

| Frequently Found Impairments of STORCH Congenital Infections | | | | | |
|---|---|---|---|---|---|
| | Syphilis | Toxoplasmosis | Rubella | CMV | Herpes |
| Eye/vision impairments | X | X | X | X | X |
| Ear/auditory impairments | X | X | X | X | X |
| Anemia | X | X | X | X | X |
| Brain calcifications | | X | | X | |
| Bone abnormalities | | | X | | |
| Congenital heart deffects | | | X | | |
| Encephalitis | X | X | X | X | X |
| Hydrocephalus | | X | X | X | X |
| Jaundice | X | X | X | X | X |
| Liver/spleen enlarged | X | X | X | X | X |
| Low birth weight | X | X | X | X | X |
| Low platelet count | X | X | X | X | X |
| Microcephaly | X | X | X | X | X |
| Pneumonia | | | X | X | X |
| Seizures | X | X | X | X | X |
| Skin rash | X | X | X | X | X |

*Table 3 Frequently found impairments of STORCH*

## *Congenital Syphilis*

Congenital syphilis is an infection (by the Treponema pallidum bacteria) which is transmitted from the untreated infected mother to the fetus. Although it is one of the oldest and most easily preventable infections of the STORCH group, there has been an increased incidence of congenital syphilis occurring in the United States (Rolfs & Nakashima, 1990).

The mother acquires this infection through sexual contact with another person who has the infection. The infection progresses through a series of stages. In the first stage, primary syphilis, a localized lesion develops at the site of the initial infection. Often the pregnant mother who has typically acquired this infection through sexual contact with an infected individual does not realize the significance of the disease and may not seek treatment. If left untreated, secondary syphilis will develops in

which the disease may extend to the skin, mouth, genital area and central nervous system. The infection may progress into the third stage, known as tertiary syphilis. in which the infection spreads to the adult's organ system. During any of these stages, the syphilis infection could be transmitted to the fetus through the placenta.

Congenital syphilis occurs in two forms. In the first form, congenital syphilis may present itself at birth or early infancy. This is known as early congenital syphilis or infantile syphilis. The infant may have skin lesions, lymph node involvement, blood stained nasal discharge, and have an "old-man" look. Multiple organ involvement may be present. Organs especially affected include: the central nervous system, liver, lungs, bones, skin and kidney (Regenbogen & Coscas, 1985; Williamson & Demmler, 1992). Some infants also have seizures, hydrocephalus, meningitis, and mental retardation (Berkow, 1987). Approximately 25% of infants die in first few months (Anderson, Bale, Blackman, & Murph, 1986).

Many infants born with congenital syphilis remain in a latent stage where symptoms are not present at birth. This second form is known as congenital syphilis tarda. Approximately one third of these individuals develop symptoms in childhood, adolescence or adult life. If symptoms develop, there may be ulcers, vision and hearing impairments, paralysis or wasting away of tissue (atrophy) as well as other neurological abnormalities. For some individuals, symptoms may never develop.

### *Visual and Auditory Impairments*

The most frequent finding in congenital syphilis is eye abnormalities. Eye conditions such as interstitial keratitis, astigmatism, chorioretinitis, iridocyclitis, glaucoma and optic atrophy may be present.

Forty percent of individuals affected with the latent form of congenital syphilis develop what is known as interstitial keratitis. Typically this occurs between five years of age and late teens. Usually both eyes are involved. This condition typically follows three stages: onset, full development and recovery. During the onset stage (1-2 weeks), there is a cloudiness on the cornea with impairment of visual acuity. For more that fifty percent of affected individuals, this begins in the periphery and advances centrally. The full development phase results in the cornea becoming very red and inflamed. A ground glass appearance is present on the cornea, obscuring the iris. There is usually impairment of vision during this time. This phase may last from 8 to 16 weeks. During the recovery stage, which may last from 1 to 2 years, clearing begins at the periphery and moves towards the center. Some cornea opacity may remain or it may clear. Even if it clears completely, vision may remain impaired. Often a central corneal haze will continue to persist. From this disorder, the cornea often has some thinning and irregularities. This results in astigmatism, which interferes with visual acuity. This disorder may also result in severe interference with vision when a membrane involving the eye splits.

In congenital syphilis there is often inflammation of various parts of the eye. In approximately 20 -25% of the cases of congenital syphilis, chorioretinitis is present which is an inflammation of the choroid and retina (Regenbogen & Coscas, 1985). This may result in diminished and hazy vision (Berkow, 1987). Iridocyclitis

(inflammation of the iris and ciliary body) may be present as a wide spread inflammation of the anterior portion of the eye. From these inflammations, scarring, secondary glaucoma, atrophy (wasting away of tissue) of the optic nerve, and retinal detachment may occur.

A sensorineural hearing loss is often present in individuals with congenital syphilis. This hearing impairment may occur in early childhood (as in approximately one third of the cases), or later in life. There is a wide fluctuation in degree of hearing impairment present. For mild cases, there may be difficulty in only hearing the lower frequencies. A severe loss often results in poor speech discrimination with the audiogram often being flat. (A flat audiogram indicates a similar level of loss across all frequencies.) For about half of the individuals who exhibit hearing loss, it is progressive (Regenbogen & Coscas, 1985).

### *Outcomes*

Outcomes depend upon when treatment was started and the amount of tissue involvement. When therapy is started prior to the second year of life, there is usually no permanent eye damage. Medication can be given to clear the cornea with a 85-90% success rate (Regenbogen & Coscas, 1985). When treatment is begun late, deficits in vision may still occur. As for hearing, aggressive treatment may decrease or stop the progressive loss of hearing. However, a hearing impairment typically remains.

## *Congenital Toxoplasmosis*

Toxoplasmosis is an infection (with the Toxoplasma gondii) by a parasite which is transmitted to an adult from contact with infected cat feces or meat (especially pork) which has not been completely cooked. In the healthy adult, symptoms are very mild or nonexistent. However, if a pregnant women contracts this infection, the infection may be transmitted to the fetus.

There is a large range of symptoms which can occur to the child born with congenital toxoplasmosis. Congenital toxoplasmosis acquired during the first trimester of pregnancy typically results in the worst symptoms with the possibility of brain abnormalities (including hydrocephalus, microcephaly, and intracranial calcification). Enlargement of the liver and spleen, anemia and decreased platelets may also occur. On the other extreme, congenital toxoplasmosis contracted during the third trimester of pregnancy often results in the infant having no symptoms.

Neurodevelopmental abnormalities from the infection may occur months or years after birth. Some possible abnormalities include seizures, psychomotor disturbances, cerebral palsy, and mental retardation. (Anderson, Bale, Blackman, & Murph, 1986; Berkow, 1987; Williamson & Demmler, 1992).

### *Visual and Auditory Impairments*

Visual impairment from congenital toxoplasmosis ranges from a mild vision loss to blindness. Chorioretinitis (an inflammation of the retina and choroid area) may occur and result in diminished and hazy vision. Complications of this can result in blindness. Retinal detachment (Lucas, 1989) and cataracts have also been present in children with congenital toxoplasmosis (Martyn & DiGeorge, 1987). Actual death of tissue in the retina (necrosis) may be present (Berkow, 1987).

A sensorineural hearing loss resulting in damage to the inner ear may also occur. This may be present at birth or develop later when no other symptoms are present. Degree of hearing loss varies. A profound hearing loss can occur (Berkow, 1987).

### *Outcomes*

If blood tests are done and the mother is found to have toxoplasmosis, drug treatment will be given to try to reduce the risk of transmission to the fetus (Daffos, Forestier, Capell-Pavlovsky, et. al., 1988). Although medication will be given to the infant with congenital toxoplasmosis to kill the organism and prevent further damage, prognosis remains poor when it was acquired during the first trimester. Routine eye exams will be necessary due to the risk of eye impairment occurring later after birth.

## *Congenital Rubella*

Rubella (also known as German measles) was the most common viral cause of birth defects until a vaccination was developed (Anderson, Bale, Blackman, & Murph, 1986). In children and adults who have acquired Rubella, only mild symptoms are typically present. However, when a pregnant mother is infected with the Rubella virus, transmission of the virus to the fetus can result in multiple impairments.

Infants with congenital rubella may present with several abnormalities or may be symptomless. Abnormalities which may be present include cardiac defects, (patent ductus arteriosus, ventricular septal defects), vision and hearing defects and some organ involvement. Additional abnormalities include: low birth weight, liver and spleen enlargement, inflammation of the brain, microcephaly, decreased platelets (thrombocytopenia), jaundice, anemia, swelling of the lymph nodes (adenopathy), abnormalities with balance (from vestibular involvement), and inflammation of the lungs (pneumonitis). Other organs may be involved as well (kidney, skin and bones).

Long term outcomes for children born with symptoms of the Rubella virus consist of a continuation of some degree of long term impairment. Hearing and vision losses continue. Seizures and cerebral palsy may occur. Although most children with congenital rubella have normal intelligence, mental retardation has been found in some children.

Disorders may emerge long after the acute original rubella infection is over, even in children who had no symptoms of the infection at birth. Children may develop

encephalitis (inflammation of the brain) with concomitant learning deficits and behavioral disturbances (Desmond, Wilson & Vanseman, 1985). Other problems such as lack of motor coordination may occur. These changes may take a long time to manifest themselves, occurring from age 2 to 7, with an increase in severity occurring up to twelve years of age (Wolff, 1985). In some cases, hearing losses have been found to occur later in adolescence. Visual impairments have been found to progressively worsen. Close monitoring is necessary throughout the person's life for possible complications occurring from having congenital rubella (Williamson & Demmler, 1992).

### *Visual and Auditory Impairments*

Multiple abnormalities may occur to the eye in infants born with congenital rubella. This involves cataracts, abnormalities to the cornea, iris, ciliary body and retina, glaucoma, microphthalmus (small eyes) and various ocular motor disorders.

Cataracts are the most common eye manifestation. It is a clouding of the lens of the eye and it is usually present at birth, occurring in one or both eyes. Cataracts may be surgically removed. However the combination of cataracts and other abnormalities of the eye often result in poor visual acuity.

The cornea of the eye may present with clouding which may clear or remain as a haze. The cornea may also possibly change shape resulting in poorer refractory power of the eye (keratoconus). Swelling of the cornea may also be present (acute hydrops of the cornea) (Wolff, 1985).

Abnormalities of the iris and ciliary body may be present. This may include inflammation, atrophy (wasting away), or tissue death in parts of the iris and ciliary body. This may result in pain, redness, photophobia (intolerance of light) and diminished vision. Absence of the muscle which dilates the eye may also be present.

A disorder of the retina (pigmentary retinopathy) is often present and may be progressive. There is often good visual acuity with this, although there have been some cases with a decrease in visual acuity to 20/60. One or both eyes may be involved with central, peripheral irregularities distorting vision (Wolff, 1985).

About ten percent of the children with congenital rubella will develop glaucoma (Wolff, 1985). Glaucoma is a disorder which has increase pressure in the eye due to more eye fluid in the anterior chamber being present than can be absorbed. The increased pressure can cause visual impairments ranging from a slight loss of vision to complete blindness. Typically there is poor visual acuity. Unfortunately in congenital rubella, glaucoma may occur long after the virus is thought to be unable to produce any new disorders.

Physical abnormalities of the eyes may be present such as micropthalomic (small eyes). This may be accompanied with a small brain and small head.

Several disorders involving the movement of the eye may occur in twenty percent of children with congenital rubella. Strabismus, which is when the eye(s) deviate from correct alignment, are often present. It can result in diplopia (double vision) or the

lack of use of one eye. Nystagmus, which is involuntary cyclical movements of the eyeball, may occur. Ocular torticollis, may also be present (Wolff, 1985).

Optic nerve atrophy and deficits in the visual cortex may also occur in congenital rubella. In both of these conditions, minimal visual loss to a total loss of vision can occur. Severe refraction errors, especially myopia (near-sightedness) may also be present. It is not uncommon to have acuity worse than 20/200.

As for hearing, a sensorineural loss is the most common long term problem. It is typically present in both ears, but if can involve only one. Degree of hearing impairment varies from mild hearing impairment to profound deafness. Usually the individual is not totally deaf, but can hear high-pitched sounds. Audiogram often show a "belly-up" curve with the greatest loss at 1000 Hz. Poor speech discrimination can occur (Regenbogen & Coscas, 1985). A mild conductive loss may also be present. Many infants who were born without symptoms of Rubella later developed deafness (Anderson, Bale, Blackman, & Murph, 1986). Often the hearing loss is progressive.

### *Outcomes*

At this time, there is no effective antiviral treatment (medication) for congenital rubella. Surgery may be performed on the eye when cataracts and glaucoma are present, with varied success. Prescriptive lenses and hearing aids may be prescribed.

The infant with congenital rubella may excrete the virus for six months or much longer. Nonimmunized pregnant women should exercise caution with interaction with infants still shedding the virus.

## *Cytomegalovirus (CMV)*

Cytomegalovirus is an infection which is commonly acquired with little to no symptoms by most healthy individuals before they are fifty years old (Anderson, Bale, Blackman & Murph, 1986). There are typically no impairments resulting from this infection in healthy individuals. However, if CMV is transmitted from the pregnant mother to the fetus, the unborn child may be severely affected.

There are a wide range of symptoms in the infected infant, ranging from no symptoms or impairments to severe or fatal involvement. Possible symptoms and complication include damage to numerous organs (including brain, liver, spleen, heart, and kidney), decreased platelet count (thrombocytopenia), skin rash, and microcephaly (decrease growth of head and brain). Stillbirth, miscarriages and death shortly after birth have occurred.

Long term outcome of children born with symptoms of CMV include mental retardation, motor abnormalities and seizures (Anderson, et. al., 1986). Cerebral palsy, hearing and vision losses may occur as well. Specific learning disabilities may occur in those individuals with normal intelligence (Williamson, Desmond, LaFevers, Taber, Catlin & Weaver, 1982).

Children who were exposed to CMV congenitally, but were born without symptoms, are at risk of developing problems later. Sensorineural hearing loss may occur later. Some studies suggest that mental retardation and cerebral palsy may also occur (Hanshaw, Scheiner, Mosley, Gas, Abel, & Scheiner, 1976; Coboy, Pass, Stagno, et.al., 1986).

### *Visual and Auditory Impairments*

Several eye disorders may be present causing visual impairments and blindness. Retinitis (inflammation of the retina) is common and may result in blurred vision and vision loss. Unlike toxoplasmosis, if retinitis is not present at birth, it will not typically occur later in life even when the virus is present.

Associated with retinitis may be optic atrophy which is a wasting away of the optic nerve. Vision loss is proportional to amount of nerve damage. Total blindness is possible.

Several other eye abnormalities may occur. Anophthalmia (absence of the eyeball) may occur. Coloboma may also be present. Iridocyclitis, or inflammation of the iris and ciliary body may also occur in which the person has severe pain, redness and photophobia (intolerance of light). Other problems include defects in tissue development of the optic nerve (Egbert, 1985) and cataracts (Martyn & DiGeorge, 1987).

A sensorineural hearing loss is the most common late developing symptom of the congenital infection. The amount of hearing loss ranges from mild to profound. More often it will occur in both ears and may be progressive (Morgan, 1987).

### *Outcomes*

There is no effective medical treatment available for congenital cytomegalovirus.

The virus may be shed by the infant with congenital CMV for years. CMV may be present in the urine, saliva, blood, tears, stool, cervical secretions and semen of individuals with congenital cytomegleovirus. Unless proper infection control measures are used (e.g. proper handwashing technique, proper disposal of wastes, cleaning environmental surfaces) persons working with the infant or young child may acquire the infection. If this is the case, symptoms are usually minimal, but the pregnant women may pass it on to her fetus.

## *Neonatal Herpes Simplex Virus (HSV)*

Neonatal herpes simplex virus causes serious illness and high death rate in newborns. There are two types of this virus: Type 1 which causes most cold sores and Type 2 which results in most genital lesions. Approximately 80% of the neonatal herpes simplex virus infections are caused by type 2 (Berkow, 1987).

Most STORCH infections are acquired from the mother by transmission of the virus through the bloodstream to the placenta and then to the fetus. Neonatal herpes,

however, is typically acquired during birth as the infant passes through the infected birth canal, or by the infection ascending upwards to the fetus after the amniotic membranes have ruptured.

Symptoms usually appear between the first and second week after birth, but may not appear until the fourth week. Initially skin vesicles appear and often lead to a more serious form of the disease unless treatment is begun. (Approximately 15% of the infected infants will have no skin lesion, but will develop encephalitis (inflammation of the brain). Other symptoms which develop include drowsiness, respiratory problems, hypotonia (low tone), hepatitis (inflammation of the liver) and diseases of coagulation. Seizures and coma are possible with brain involvement (Berkow, 1987).

Infants with this infection fall into three classifications. The first classification is known as neonatal herpes simplex. In neonatal herpes simplex, clotting disorders (disseminated intravascular coagulation) and organ abnormalities are present (especially the liver and lungs). In this category, inflammation of the brain or skin abnormalities may or may not be present. The mortality rate for this category is the highest.

The second and third categories are both called localized disease. In one of the these, inflammation of the brain (encephalitis) with neurological abnormalities are present. The other type of localized disease is where only the skin, eye, and mouth are involved (Gammon & Nahimias, 1985).

### *Visual and Auditory Impairments*

There are a wide range of eye problems in children with neonatal herpes. On the one extreme there may be a mild eye problem such as conjunctivitis (inflammation of the membrane which lines the eyelid and goes around the eyeball) which causes no vision problems. On the other extreme there can be severe optic nerve atrophy (wasting away of the optic nerve) or retinitis (inflammation of the retina) which can lead to blindness (Anderson, Bale, Blackman, & Murph, 1986; Gammon & Nahmias, 1985).

Several other eye disorders may be present. Inflammation, lesions, and cloudiness of the cornea may be present (keratitis) which may lead to a vision loss. Uveitis, inflammation of the iris, ciliary body and/or choroid, may also occur. When the inflammation is only to the back portion of the eye containing the choroid and retina, a condition known as chorioretinitis occurs in which diminished vision and blindness may result. If inflammation of the optic disk is present, optic atrophy and possible blindness may occur (Gammon & Nahmias, 1985).

Occasionally there may be retina detachment where the retina tears and partially separates from the back of the eye resulting in vision loss unless surgically replaced. Surgery must be done immediately or serious vision loss will occur.

Cataracts (a clouding of the lens of the eye) may result in which vision in blurred.

The eye muscles may be affected resulting in strabismus. One or both eyes deviate inward, outward up or down directions. Double vision may result or one eye may not be used.

The spread of herpes simplex virus into the brain may result in defects of the visual pathway. Affected individuals may have visual field deficits where the right or left field of vision is gone in one or both eyes. Vision loss in one fourth of the visual field (quadrants) may also be involved.

Other possible eye problems include microphthalmus (small developed eye) and microcornea (small cornea).

Children infected with neonatal herpes simplex are in the high-risk category for developing hearing loss (Morgan, 1987).

### *Outcomes*

Prompt treatment of this infection increase the likelihood of survival as well as increasing the number of infants who will develop normally (from 10 % to 35%) (Berkow, 1987).Prognosis depends on the extent of the disease. Some children with the disseminated form will have 20% to 30% chance of having multiple impairments including poor growth, mental retardation and blindness (Anderson, Bale, Blackman & Murph, 1986).

Neonatal herpes simplex can often be prevented if the infant is delivered by caesarean section within four hours of amniotic membranes rupture (Nahmias, Josey, Naib, Freeman, Fernandez & Wheeler, 1971).

## *Other Infections: HIV (AIDS Virus)*

Since the original description of STORCH infections, other agents have been linked to congenital infections which do not share the distinctive characteristics of the STORCH infections. One of these infections the HIV virus (human immunodeficiency virus) which attacks the immune system and can lead to AIDS (acquired immune deficiency syndrome). The majority of infants or children under age 13 who have AIDS acquired the HIV virus from their infected mother. This can occur one of the following ways:(1) during gestation where the virus crosses the placenta, (2) during delivery by contact with maternal blood, or (3) by breast feeding. (Other less common means of transmission in children under 13 is associated with contaminated blood in a blood transfusion and child abuse (Caldwell & Rogers, 1991). Adolescents typically acquire the infection through sexual intercourse with an infected person or through contaminated needles typically used for illegal drugs. Since the blood is now screened, a very small percent received the infection through contaminated blood.

Several strands of the HIV virus have been found (HIV-1, HIV-2) (Levy, 1990). A child may be HIV-positive (i.e. have HIV), but not develop symptoms for years. The child may then develop the AIDS syndrome in which symptoms of an injured

immune system arise. Infants and young children with AIDS have variable and non specific symptoms such as: failure to thrive, developmental delay, enlarged liver and spleen, chronic diarrhea, lymphadenopathy, upper respiratory infection, ear infection, thrush and recurrent pneumonia (Anderson, Bale, Blackman & Murph, 1986).

Infants and children with AIDS do not usually have the early opportunistic infections and cancers which adults with AIDS acquire. Instead, infants and children develop secondary infections and recurrent bacterial infections which can lead to sepsis and meningitis. The most common secondary infections in children include Pneumocystis carinii pneumonia (PCP) and Lymphocytic interstitial pneumonitis (LIP) (Caldwell & Rogers, 1991). Infections such as cytomegleovirus and toxoplasmosis may occur in the infant or child with AIDS and adversely affect various organ systems (Levin, Zeichner, Duker, Starr, Augsburger, Kronwitch, 1989; Mitchell, Erlich, Mastrucci, Huto, Parks, Scott, 1990).

Children with congenital AIDS are also at risk of acquiring infections which immunizations are suppose to provide protection. This is because a child with AIDS is unable to mount proper antibody response to immunizations. Therefore, immunizations do not afford any protection from the infections, and a child could die of measles, for example (Rubinstein, 1989).

Children with AIDS often have central nervous system involvement. Some have microcephaly, progressive encephalopathy, progressive dementia and severe spasticity (Lyman, Dress, Dore, Rashbaum, Rubinstein & Soeiro, 1990; Rubinstein, 1989). Developmental problems such as mental retardation, developmental delays, cognitive deterioration and other neurological impairments and motor abnormalities have been found in some children with AIDS typically within the first five years of life (Diamond, 1989).

Individuals who acquired AIDS in later childhood or early adulthood have some differing symptoms and secondary diseases. Symptoms usually reflect the injured immune system and may include: fatigue, weight loss, intermittent fever, malaise, lethargy, chronic diarrhea, enlarged lymph nodes, dry cough, thrush and a tendency to bruise easily. Neurologic involvement may occur as well with seizures,hallucinations and progressive dementia (Berkow, 1987).

Adolescents and young adults with AIDS acquire opportunistic infections. These are infections which are not a threat to a healthy immune system, but can be fatal to a person with AIDS due to their impaired immune system. Cytomegalovirus and toxoplasmosis are two opportunistic infections which when acquired after birth in a person with AIDS, may have devastating results. Two other acquired diseases include pneumocystis carinii pneumonia and Kaposi sarcoma which may be fatal (Berkow, 1987).

Some children and adults develop AIDS Related Complex (ARC). In this condition, many of the same symptoms are present as with those with AIDS, but the individual does not usually have the typical opportunistic infections or Kaposi sarcoma.

Whether this condition always progresses at some point to full blown AIDS, has not been conclusively determined.

Risk of transmission of the HIV virus is extremely low. Transmission typically occurs from sexual encounters with infected individuals, IV drug use with a contaminated needle or congenital transmission. AIDS can not be transmitted by casual contact. One study examining preschool children with HIV found no transmission of the virus to their household contacts when sharing beds, toilets, utensils, toothbrushes occurred or by hugging or kissing (Rogers, White & Sanders, 1990). Other studies have supported the lack of transmission by casual contact (Berkow, 1987).

### *Visual and Auditory Impairment*

Individuals with AIDS are at risk of having visual and auditory impairments. Several visual impairments have been found (often in conjunction with secondary infections such as those found in the STORCH mnemonic and meningitis). Some eye abnormalities include chorioretinitis, CMV retinitis, ocular motor nerve palsy, cortical visual impairment, gaze palsy and visual field defect (Mansour, 1990). These conditions may result in mild to severe visual impairment, including blindness. The individual with AIDS is also at risk of having a hearing impairment due to general neurologic impairments and acquisition of such infections as meningitis.

## *Other Teratogens*

Other teratogenic agents exist which may adversely affect the fetus and cause impairment. These other teratogens which can effect vision and hearing include medication and illegal drugs taken by the mother during pregnancy and alcohol.

## *Medications/drug Abuse*

Prescription medications or illegal drugs which have been taken during pregnancy may affect the fetus in several different ways. One way is that the drug may directly affect the embryo which results in birth defects, toxic effects or death to the embryo. Another possibility is that the drug may interfere with the efficient functioning of the placenta. A decrease in the placenta's ability to exchange nutrients and oxygen with the fetus may occur. The drug could also upset the biochemical balance of the mother, adversely affecting the fetus (Bekow, 1987).

Multiple birth defects may occur from some medications and illegal drugs. However, most of them do not cause damage to the eyes or ears. Of those that do, the antibiotics have been especially linked to visual and auditory impairments. The tetracyclines, for example, have been en considered a possible cause of congenital cataracts. Other antibiotics such as streptomycin, gentamycin, and karamycin may damage the fetal labrythine and result in a hearing loss (Berkow, 1987). Developing deaf-blindness from this cause is rare.

## Fetal Alcohol Syndrome (FAS)

Alcohol consumption during pregnancy places the fetus at risk of being born with multiple abnormalities. The combined effects of maternal (and possible paternal) alcohol consumption on the infant/child has been referred to as Fetal Alcohol Syndrome (FAS).

The characteristics of FAS depend upon the timing and amount of alcohol consumption. Some of the major characteristics include prenatal and postnatal growth deficiency, delay of gross and fine motor development, congenital malformation and microcephaly. Additionally, FAS is the most common cause of mental retardation. Some less frequent abnormalities resulting from FAS include: joint abnormalities, cardiovascular defects and failure to thrive (Berkow, 1987; Blackman, 1990). Behavior problems and hyperactivity may be present.

### Visual and Auditory Impairments

Both vision and hearing impairments have been found in FAS. Congenital optic nerve hypoplasia has been described as occurring as well as myopia. Both conductive and sensorineural hearing disorders are more frequent in children with this syndrome.

### Outcomes

As the child grows older, he may continue with cognitive and behavioral difficulties. An unstable home environment may attribute to these problems continuing.

## Possible Effects of Teratogens: Hydrocephaly and Microcephaly

Hydrocephaly and microcephaly may occur due to prenatal exposure to teratogenic agents (such as CMV and toxoplasmosis) or from other causes. Both may cause brain damage which can severely affect the child.

In hydrocephaly, there is an excessive accumulation of cerebral spinal fluid in the ventricles (small cavities) in the brain. This is typically due to a blockage of the flow of spinal fluid which circulates through the ventricles, spinal column and around the brain. A blockage of the cerebral spinal fluid results in an accumulation of the fluid in the ventricles which gives the infant or very young child an abnormally large head. The excess fluid causes the ventricles to distend in the infant, toddler, child or youth and results in compressing parts of the brain. (This occurs whether or not the head enlarges.) The compressing of the brain can damages the brain and may result in spastic paralysis of the legs, seizures, or mental retardation (Bleck, 1982).

Microcephaly is an abnormally small head due to impaired brain growth and development. There are many conditions which cause microcephaly, some of which have been described earlier in this monograph. Isolated microcephaly can also occur

which may be familial. Microcephaly is often associated with varying degrees of cognitive impairment and may be associated with other signs of dysfunction such as cerebral palsy, and seizures.

### *Visual and Auditory*

Children with hydrocephalus are at risk of developing visual impairments such as optic atrophy. Hearing impairments are more rare. Many of the conditions which cause microcephaly are associated with vision and hearing problems.

### *Outcomes*

In hydrocephalus, a permanent drainage system is surgically put in place. This drainage system is a long small tube known as a shunt which is placed in a ventricle in the brain and usually ends in the abdominal cavity. The shunt is able to drain off excess cerebral spinal fluid from the brain to another part of the body. This prevents pressure from building up on the brain and will prevent further damage from occurring.

In microcephaly, nothing is usually specifically done for the size of the brain, but the symptoms are treated.

Visual and hearing impairment usually continue unchanged.

## *General Outcomes of Teratogens*

The outcome for the infant who has been exposed to teratogens varies greatly. Those infants who have been exposed to STORCH congenital infections have a higher risk of visual and auditory impairments as opposed to some of the other types of teratogens.

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Chapter 6

# *Prematurity and Small for Gestational Age*

Newborns who are premature or small for gestational age are at risk of having multiple impairments and complications. The immature or developing visual and auditory system may be negatively impacted in both premature infants and infants born small for gestational age. The difference between these two conditions, and their varying affect on vision and hearing will be discussed.

## *Prematurity*

In the past, definitions of prematurity included the timing of the birth and the weight of the infant. Usually an infant who was born before 37 weeks of gestation or who weighed less than 5.5 pounds was considered premature. Several authorities have shifted away from these definitions since it does not differentiate between a baby born after 37 weeks of gestation and weighing less than 5.5 pounds and one who is born early. Both may have very different problems and outcomes. To address this difference, the term premature is being used to refer to infants who are born before the 37 week of gestation.

A variety of causes result in infants being born premature. Early contractions result in the birth of a premature infant and this occurs more frequently in adolescent pregnancies (Block, Saltzman & Block, 1981). Women carrying multiple fetuses or who have had many pregnancies and weak cervical muscles are at greater risk of having premature infants (Batshaw & Perret, 1986). Prematurity also occurs more often in women who develop an infection during the third trimester or who have taken such illegal drugs as cocaine. Women who have such chronic illness as diabetes are also more likely to have a premature child (Niswander & Gordon, 1982). Most frequently the cause is unknown.

Multiple problems and complications may be present for an infant who is premature. Most problems of prematurity are due to immature functioning of organ systems. Often the lungs, heart, central nervous system, GI tract, and kidneys are affected with metabolic problems. The lungs are at risk of developing respiratory distress syndrome (formerly known as hyaline membrane disease) in which the small air sacs (alveoli) in the lung collapse resulting in inadequate air exchange. A heart condition known as patent ductus arteriosus may occur in which a blood vessel (vascular connection between the aorta and pulmonary artery known as ductus artrioses) which usually closes ar birth remains open. This may result in heart failure. An immature central nervous system may result in apnea (periods of not breathing) and an increase incidence of sudden infant death. Also, an immature central nervous

system may result in inadequate sucking and swallowing reflexes which leads to poor nutrition. If the kidney is not completely functioning, it may be unable to adequately excrete unneeded acids without medication.

Metabolic problems may also be present in prematurity. The infant is at risk of being hypo or hyperglycemic (too little or too much sugar) as well as having hyperbilirubinemia (too much bilirubin). Typically the infant can not adequately regulate his/her own temperature and is more at risk of developing infections (Yu, 1987).

### *Vision and Hearing Impairments*

A greater incidence of visual impairments are present in infants who are premature. In one regional survey, approximately 4.3% of the premature infants had serious visual defects as opposed to 1.5 per 1000 children in the community (Alberman, Venson, & Evans, 1982).

The visual system is incomplete at birth, with the peripheral retina of each eye being incompletely developed. Infants who are born prematurely may have an interruption in the normal development of the peripheral retina, and vascular abnormalities can occur (Biglan, Van Hasselt, & Simon, 1988). The most common cause of blindness associated with prematurity is retinopathy of prematurity. In this condition, there is an abnormal growth of blood vessels which occur in the immature retina. The effects of this may range from no impairments with spontaneous regression of these abnormal blood vessels, to possible retinal detachment and blindness. Glaucoma may also occur with the retinopathy of prematurity.

Other visual conditions associated with prematurity are optic atrophy, squints, refractive errors and cataracts of prematurity. Optic atrophy is often associated with severe cerebral palsy. Squints and refractive errors may be related to retinopathy of prematurity (Yu & Wood, 1987). Cataracts of prematurity present as cloudy areas on the lens of the newborn's eyes which usually disappear after a few weeks (Martyn & Di George, 1987).

There is a greater incidence of serious hearing impairments in infants born prematurely. Decades ago the incidence as reported as high as 9%, but more recently has decreased to closer to 2% (Yu, 1987).

Several causes may be responsible for the hearing impairments. In prematurity, the underdeveloped blood vessels of the inner ear can easily hemorrhage (bleed), which would decrease the blood supply to the Organ of Corti. Toxic and irreversible effects can occur on the cells in the area (Yeates, 1986). Conditions which are associated with premature infants have been associated as attributing to sensorineural deafness. This includes hypoxia and hyperbilirubinemia. Incubator noise has been debated as contributing to sensorineural deafness. However, most authorities have ruled this out (Morgan, 1987).

If the birth is traumatic, the temporal bone may break which result in bleeding in to the inner ear or brainstem which may interfere with hearing (Morgan, 1987).

## *Small for Gestational Age*

The term small for gestational age (SGA) (also termed intrauterine growth retardation) is used to refer to any infant below the 10th percentile for gestational age. The infant is considered small for gestational age when meeting this criteria regardless if the infant was premature, full-term or postterm (Berkow, 1987). There are also several factors which may result in a baby being small for gestational age. One causative factor may be inadequate nutritional intake during pregnancy. Chronic maternal illnesses, congenital infections and maternal drug use have also been associated with an infant being born small for gestational age. The pregnant women who is over forty years of age, has an increase incidence of giving birth to an SGA infant. This may be due to inadequate blood supply to the placenta resulting in an unsatisfactory nutritional supply to the fetus (Scott & Jordan, 1972). Genetic and inherited factors may also result in this condition as well.

Infants who are small-for gestational age typically exhibit the same developmental delay as the same aged normal sized infants. If the SGA infant is also born premature, those described conditions resulting from immature systems may be present. The SGA infant is attributed as having a greater incidence of major congenital abnormalities (Blackman, 1990) (although a few researchers disagree with this conclusion, but results are based on small sample size (Grogaard, Linstrom, Parker Colley & Stahlman, 1990). Often the SGA infant does not catch up in terms of size as a premature infant would, but may remain small and underweight throughout his or her life (Blackman, 1990; Starfield, Shapiro, and McCormick, 1982). A higher incidence of developmental disabilities, learning disorders, attention deficit disorders, mental retardation and cerebral palsy has been found (Allen, 1984).

### *Vision and Hearing Impairments*

Infants who are born SGA are at greater risk of having visual and auditory impairments. Since infants who are SGA may also be premature, they are at risk of having the visual and auditory impairments described above. Additionally, the infant may be SGA due to maternal infection or drug abuse. As discussed earlier, the STORCH syndromes and drug abuse can be the cause of several types of visual and auditory impairments. The reader is referred to the previous chapter for more information regarding these.

### *Outcomes of Prematurity and Small for Gestational Age*

Infants who are born prematurely or SGA are at risk for vision and hearing impairments. However, due to the multiple problems, associated conditions and variety of impairments, one single cause can not often be conclusively identified as the etiology. Outcomes would depend upon the specific condition and degree of impairment.

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# Chapter 7

## *Adventitious Conditions*

Development of concomitant visual and auditory impairment may be acquired after birth from accidents, child abuse, tumors, stroke, and post-natal infections. Accidents and child abuse may cause direct trauma to the eye and ear, affecting the external or internal mechanism. Accidents and child abuse may also result in severe head trauma or asphyxia which results in brain damage. This in turn may cause impairment in the visual and auditory processes. Tumors may arise in the eye and ear or along the pathways leading to the brain or in the visual and auditory cortex. A stroke may also occur affecting vision and hearing. Post-natal infections of meningitis and encephalitis also may occur causing vision and hearing impairments.

### *Direct Trauma to the Eye and Ear*

Accidents or child abuse may cause direct damage to the eye and ear. The range of impairments vary greatly as to the type of damage caused by the accident. Injury directly damaging the eye or ear may be minor or severe. The eye may be punctured by an object or the retina may detach from the accident. Cataracts and glaucoma may also occur from the trauma as well. Damage to the retina may result in scotomas (blind spots in the field of vision). Decreases in visual acuity and blindness is possible.

In battered baby syndrome, hemorrhages (bleeding) in the eye, often around the macula and optic nerve may occur in both eyes. Damage to the retina in this syndrome may cause blindness (Buncic, 1987).

Hearing loss may occur from a displaced ossicular chain, perforation of the eardrum, or temporal bone fracture from a severe blow to the ear or head.

### *Severe Head Injury*

Severe head injury results in injury to the brain and may cause both vision and hearing impairments. This occurs when the areas of the brain which interpret visual and auditory input or their connecting pathways are damaged. The type of accident may be classified as an open or closed head injury. In an open injury, the skull has been penetrated or crushed. Examples of an open injury would include a gunshot wound to the head or a heavy object falling on the head. In closed head injury, the skull remains intact and the damage occurs from movement of the brain against the

skull. This type of injury more commonly results in visual and auditory impairments. Most car accidents and child abuse (which involves severe shaking of the infant or striking the infant/child's head), results in closed head injury.

To understand the mechanics of closed head injury, the reader must be aware that the brain is "floating" or surrounded by a fluid known as cerebral spinal fluid. The brain is then protected by the skull. When a car accident, bicycle accident, fall, or violent shaking occur, the brain is displaced forward, hitting against the interior of the skull (this site of damage is known as the coup). The brain then bounces back and hits the opposite side of the skull. (This area of damage is known as the contra-coup). The brain then shifts back and forth hitting these two areas of the brain against the skull several times, resulting in damage at the two sites. However, more diffuse brain damage occurs as the brain rotates as the impact takes place. Damage also occurs as nerve pathways throughout the brain break. The rough bones at the skull base cause further brain damage to that area. Often there will be swelling (edema) and bleeding (contusion, hematoma or hemorrhage) in the brain which can increase the pressure on the brain, causing pressure on the blood vessels and decreasing their flow. When that occurs, further tissue death occurs due to the inadequate blood flow. Several problems may occur as a result of head trauma (see Table 4). Included in this is frequent vision and hearing impairments.

**Traumatic Head Injury**

**Disorders in the cognitive area may include:**

1. attention and concentration problems
2. memory problems, especialy new learning
3. perceptual problems, including spatial disorientation
4. communication and language disabilities
5. poor judgment; inability to make decisions; decreased abstraction; illogical thoughts
6. confabulation; distractability; perplexity
7. decreased learning abilities; deficits in processing information
8. rigidity and inflexibility; perseveration; inability to adjust to changing contingencies

**Disorders in the psychomotor and sensory/physical areas may include:**

1. reduced motor speed
2. visual, auditory, and tactile deficits
3. quadriplegia; hemiplegia; spasticity; ataxia; rigidity states; tremors
4. reduced eye-hand coordination
5. spatial disorientation
6. increased risk seizures

*Table 4 Problems occurring in head injury (cont.)*

**Disorders in the social/affective areas may include:**

1. lack of goal-directed behavior, initiative and planning
2. poor self-image; reduced self-worth
3. disinhibition; impulsivity
4. apathy; social withdrawal
5. loss of concern for others, self centeredness
6. indifference; poor grooming; denial of disability
7. family stress; disturbances in sexual behavior
8. aggressive behavior; inappropriate childlike behavior

*(Table 4 continued)*

## *Visual and Auditory Impairments*

Several types of visual impairments have been associated with head injury (see Table 5).

The most common eye problems are eye muscles palsies. These are paralysis or impairments of the movements of the eye due to impairment of the eye muscles or the nerve innervating them. These eye muscle palsies may result in diplopia (double vision) from strabismus (deviation of one or both eyes in different directions) or the lack of use of one eye(the suppression of one image by the brain). Often these extraocular palsies are reversible (Rosenthal, Griffith, Bond, & Miller, 1984).

Those eye abnormalities which cause the greatest functional impact include perceptual disorders, tracking disorders and central or peripheral types of blindness (Rosenthal, Griffith, Bond, & Miller, 1984). Perceptual disorders may result in difficulties in recognizing consistencies in shapes and color, as well as difficulty in perceiving objects against a background.

Tracking disorders may result in an inability to follow an object through space. Difficulties with vertical, horizontal and diagonal tracking may occur.

Abnormalities of field of vision may be present, especially when the optic tracts have been affected. There may a loss of half of the right or left field of vision for one or both eyes. (hemianopsia). Loss of quadrants may also occur.

Cortical visual impairments (cortical blindness) may result in which injury occurs to the portion of the brain which receives input from the eyes (occipital lobe). If the blood vessels serving this area have been compressed, cortical visual impairment may also result. Cortical visual impairment may involve a total lack of vision or inconsistent vision. If there is sudden injury, the loss is typically irreversible. Gradual injury due to brain edema (swelling) may not lead to tissue death so vision may return after a few days or months (Rosenthal, Griffith, Bond, & Miller, 1984).

| Common Visual Impairments Found in Traumatic Head Injury | |
|---|---|
| **Injury to the eye and/or its muscles** | **Neurological impairments affecting visual pathways and visual cortex** |
| | |
| Decreased acuity | Field cuts |
| Blindness | Visual perceptual deficits |
| Scotoma | Diplopia |
| Diplopia | Nystagmus |
| | Gaze palsies |
| | Tracking disorders |
| | Decreased acuity |
| | Blindness |
| | Global stereopsis impairments |
| | Color vision defects |

*Table 5 Visual impairments associated with head injury*

Optic nerve atrophy is a wasting away of the optic nerve which may result in visual loss, proportional to the amount of nerve damage. There may be decrease visual acuity to total blindness with a lack of response to direct light.

Other vision problems due to neurological impairment may exist, such as problems in perceiving color (color blindness) to nystagmus (fine rapid involuntary movements of the eye).Impairment due to head injury may result in decreased acuity, blindness and scotomata.

Hearing disorders often occur due to trauma to the ear, nerve pathways or brain. Damage in the middle ear may result from tears in the eardrum or displacement of the three bones in the middle ear. Both of these result in a conductive hearing loss. Damage to the inner ear can also occur, resulting in a sensorineural hearing loss. Although a sensorineural loss occurs frequently, it is typically mild and rarely causes functional impairment (Chamovitz, Chorazy, Hanchett, & Mandella, 1987). Damage to the auditory nerve or portion of the brain which receives and interprets messages are more likely to cause permanent hearing losses (Rosenthal, Griffth, Bond, & Miller, 1984).

## *Outcomes*

Typically there continues to be a progressive return of function within the first five years after the injury. During that time, the individual is learning how to compensate for what has been lost. Structural changes also occur in the brain (such as decrease swelling) which result in improved functioning.

The extent of vision and hearing impairment depend on the type and extent of damage.

## Accidents Involving Asphyxia

Asphyxia is a decrease in the amount of oxygen in the body. Some of the causes include choking, carbon monoxide poisoning, drowning, strangulation, electric shock, crushing chest injuries and drugs.

Infants, toddlers, children and youth who have an accident involving asphyxia may have a wide range of symptoms. Cerebral palsy, mental retardation and seizures may occur. Accidents involving asphyxia places the child at risk of having visual and hearing impairments.

## Tumors

Tumors may arise after birth which adversely affects the normal functioning of the eye and ear. For the eye, losses in visual acuity and losses in fields of vision may occur depending upon the location and type of the tumor. Consequences are more serious when the tumor is retinoblastoma. Retinoblastoma is a cancerous (malignant) tumor which develops from an immature retina. It may be inherited or develop as a mutation. This tumor can result in loss of life unless early surgical intervention occurs.

Tumors may also result in conductive or sensorineural hearing losses. This depends upon the location and severity of the tumor.

## Stroke

A stroke (also known as a cerebral vascular accident or CVA) is a disturbance in the blood flow in the brain. This results in a sudden loss of some neurological functioning. The term stroke may include transient, brief strokes (known as transient ischemic attacks (TIA) or a permanent/complete stroke (Berkow, 1987; Karanjia & Smigielski, 1988).

A transient stroke (TIA) has an abrupt onset, but resolves itself completely within twenty-four hours. It may be caused by a drop in blood pressure in the arteries of the brain or a temporary oculsion of a cerebral artery (e.g. by a clot). Symptoms of TIA depend upon the area of the brain affected. Motor weakness and numbness may occur. If the area of the brain which comprehends speech is affected, he/she may have difficulty understanding language and may appear confused. Inability to initiate speech or slurred speech may also occur when the motor area for speech is affected. Vertigo (the sensation of moving around in space or having objects move about the person) may be present as well as difficulty walking. A headache may also occur.

In a complete stroke, deficits continue past twenty-four hours. This indicates that death (infarction) of brain tissue has occurred resulting in permanent brain damage. There are several causes of a complete stroke. The major ones include obstruction of a blood vessel (by a clot or foreign substance), long periods of time with low blood pressure, and vascular spasm from a cranial bleed (subarachnoid hemorrhage) or migraine. Some less common causes include leukemia, sickle cell anemia, dehydration and trauma (Karanjai & Smigielski, 1988).

As with TIAs, the symptoms of a complete stoke depend upon the location, size and type of stroke. There may be disturbances in motor function (such as paralysis or weakness) and minor degrees of sensory loss (such as an inability to discriminate objects placed in the hand with the eyes closed). In some cases, there may be disturbances in perceiving body image where a person denies that a body limb belongs to him (anosognosia). Disturbances in language may occur where the youth may be unable to comprehend language or be unable to speak. Difficulties in recalling names of common items or problems in articulation may occur as well. Disturbances in consciousness and behavior can occur. Memory loss, apathy, lack of motivation, mental retardation and seizure disorders may also be present as well as other symptoms.

### *Visual and Auditory Impairment*

In both TIA and complete stroke, visual and auditory impairments may occur. In TIAs, a sudden temporary visual loss (amaurosis fugax) may occur which appears as a curtain descending over one eye. With both TIA and stoke, visual loss may occur in one or both eyes. Field defects, diplopia (double vision), and disturbances in ocular motility can occur. Both eyes may be deviated toward the side of the brain where the injury is located, with an inability to gaze to the opposite side (Karranjia & Smigielski, 1988). Although hearing impairments may occur, they are not as common.

### *Outcomes*

Progressive improvement in functioning is present up until 3 to 5 years after the injury.

## *Infections*

Two of the most common infections resulting in vision and hearing impairments are meningitis and encephalitis. These two infection will be discussed in terms of their general characteristics and specific visual and auditory impairments.

## Meningitis

Meningitis is an infection resulting in inflammation of the membranes (meninges) which cover the brain and spinal cord. Impairments acquired from this infection range from no impairments to possible death within hours. Prognosis depends upon what has caused the infection.

There are several different organisms which can cause meningitis. If the cause is a virus (such as from mumps), the symptoms are usually mild and pose no threat to healthy children. However if the meningitis is caused by a bacteria (such as streptococcus pneumoniae or Hemophilus influenza type B (HIB) or meningococcus), severe damage and/or death can occur. (Less often fungi, parasites, tuberculosis and spirochetes may cause meningitis with varying prognosis.)

For children and adults, typical symptoms include a stiff neck, sore throat, vomiting, headache, fever, lethargy and sensitivity to bright light. A nerve that controls the lateral movement of the eye may be affected. A progression through irritability, lethargy, drowsiness, stupor and coma is possible. For infants, symptoms vary , although fever, vomiting, seizures, high pitched cry and bulging fontanels (soft spots on top of the head) may be present.

Some affected infants or children may be left with brain damage, mental retardation, seizures and motor impairment.

### Visual and Auditory Impairment

Visual impairments, such as cortical visual impairments, may occur when neurological damage is present from a bacterial infection.

Hearing loss occurs in approximately 10% of those who survive bacterial meningitis and is typically permanent. Hearing loss may be present in one or both ears. The loss is usually due to damage to the eight cranial nerve which send impulses from the ear to the brain, or damage to the nerve endings in the inner ear. Deafness may occur, but is more likely seen in individuals who have other neurological deficits (Anderson, Bale, Blackman, & Murph, 1986).

### Outcomes

Antibiotics and sometimes corticosteroids are used to treat bacterial meningitis. Immunization with HIB vaccine in early infancy should protect more children from developing HIB meningitis. For viral meningitis, symptoms will be controlled by medications, but the infection usually subsides on its own.

Some individuals who do acquire meningitis, are left with long term conditions such as deaf-blindness.

## *Encephalitis*

Encephalitis is an inflammation of the brain. Encephalitis may result as a primary manifestation of a virus, or occur as a complication of another infection such as measles, chickenpox or rubella. In some cases the encephalitis is carried by mosquito and tic to infected individuals.

Symptoms of this infection vary. At times there may be a decrease in alertness. Other times more severe symptoms may be present such as seizures, paralysis of an arm or leg, or coma.

Depending upon the type of virus, the condition is usually mild with no lasting disabilities. However permanent brain damage can occur with mental retardation or learning disabilities, especially in infants. In a few cases children may die. Other problems which can occur include neurological impairments, seizures, behavior changes, mental retardation and motor deficits.

### *Visual and Auditory Impairments*

When brain damage results from encephalitis, blindness, visual impairments and sensorineural loss may result.

### *Outcomes*

rognosis depends upon the type of virus, but even very ill individuals may completely recover. Permanent damage is more likely to occur in infants.

# APPENDIX

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# APPENDIX F

# PROJECT DIRECTORS' MEETING AGENDAS

**Agenda**
**Project Directors' Meeting**
**November 6-8, 1990**

| | | | |
|---|---|---|---|
| Nov. 5 | 6:00 - 9:00 p.m. | Registration | Lobby |
| Nov. 6 | 7:00 - 9:00 a.m. | Registration | Lobby |
| | 9:00 - 10:00 | Opening<br>Dr. Robert Davila<br>Federal Government Officers<br>(Introductions & Discussions) | South Ballroom |
| | 10:00 - 10:30 | Meeting Orientation<br>Dr. Victor Baldwin | South Ballroom |
| | 10:30 - 11:00 | Break | |
| | 11:00 - 12:30 | Keynote Speakers<br>Dr. Rob Horner<br>Mr. Tim Fredericks | South Ballroom |
| | 12:30 - 2:00 | Lunch (catered)<br>Patricia Guard, Director, Policy and Planning | South Ballroom |
| | 2:00 - 3:30 | Focus Session #1 | (See next page for focus session locations) |
| | 3:30 - 3:45 | Grants & Contracts Services | |
| | 3:45 - 4:30 | Opportunity for: meeting with TRACES staff, informal conversation with federal officers, network with project directors, etc. | |
| | 4:30 - 6:30 | No host bar | Galaxy Room |
| Nov. 7 | 9:00 - 10:30 | Focus Session #2 | (See next page) |
| | 10:30 - 11:00 | Break | |
| | 11:00 - 12:30 | Focus Session #3 | (See next page) |
| | 12:30 - 2:00 | Lunch (catered) | South Ballroom |
| | 2:00 - 3:30 | Focus Session #4 | (See next page) |
| | 3:30 - 4:30 | Summary - Dr. Dawn Hunter /Dr. Bud Fredericks | South Ballroom |
| | | **(D/B VI-C Project Directors Only)** | |
| Nov. 8 | 8:30 - 9:15 a.m. | Reauthorization, and Federal Budget - their effects on persons with and programs for deaf-blindness | South Ballroom |
| | 9:15 - 10:00 | TAC, Curriculum Institute, TRACES, and Perkins-Hilton Project - how each can serve the 84.025A programs and vice versa | South Ballroom |
| | 10:00 - 10:30 | Data Collection | |
| | 10:30 - 10:45 | Break | |
| | 10:45 - 12:00 | TRACES Coordinators and 84.025A Project Directors | |
| | 12:00 - 12:15 | Concluding remarks | |

**PROJECT DIRECTORS' MEETING SCHEDULE**
**GEORGETOWN OMNI HOTEL, WASHINGTON, D.C.**
**November 18-20, 1991**

**Monday, November 18**

All VI-C Project Directors (Directors of Severely Handicapped Projects may choose to attend).

| | | |
|---|---|---|
| 9:00 - 9:15 | Welcome and Introductions | Phillips Ballroom |
| 9:15 - 12:00 | Federal Regulations/Grants | Phillips Ballroom |
| 12:00 - 1:30 | Lunch | |
| 1:30 - 2:00 | Child Count - Vic Baldwin | Phillips Ballroom |
| 2:00 - 3:00 | System Change - Dawn Hunter and Bruce Dalke | Phillips Ballroom |
| 3:00 - 5:00 | VI-C Coordinators meet with TRACES staff to plan technical assistance for 1991/92 | Suite TBA |

**Tuesday, November 19**

| | | |
|---|---|---|
| 9:00 - 9:30 | Federal Government Staff Address - Judy Schrag | Phillips Ballroom |
| 9:30 - 10:30 | Keynote Address - Eugene Edgar | Phillips Ballroom |
| 10:30 - 11:00 | Break | |
| 11:00 - 12:30 | Effective Practices Presentations | See attached schedule |
| 12:30 - 2:00 | Lunch | National Gallery |
| 1:00 - 3:30 | Poster Sessions | Renwick Suite |
| 2:00 - 3:00 | Networking Time | Sign-up Space Available |
| 3:00 - 4:00 | Federal Government Time - Project Management Time (Especially for newly funded projects) | Phillips Ballroom |
| 4:40 | No Host Social Hour | National Gallery |

**Wednesday, November 20**

| | | |
|---|---|---|
| 9:00 - 10:30 | Focus Groups | See attached schedule |
| 10:30 - 11:00 | Break | |
| 11:00 - 12:00 | America 2000 - Patty Guard | Phillips Ballroom |
| 12:00 - 1:30 | Lunch | National Gallery |
| 1:30 - 2:30 | Individual Time with Project Officers for VI-C Projects and Severely Handicapped Grants | Sign-up Space Available |
| 2:30 - 4:00 | Focus Groups | See attached schedule |

**Severe Disabilities Branch**
**Office of Special Education Programs**
**U. S. Department of Education**

**Annual Project Directors' Meeting**
**October 26-28, 1992**

**Monday, October 26, 1992**

**Directors of State/Multi-State Services to Children with Deaf-Blindness**

| | | |
|---|---|---|
| **8:00** | **Coffee & Pastries** - Salon I | |
| **9:00** | **Welcome & Introductions** - Salon I | Dawn Hunter, Chief<br>Severe Disabilities Branch, OSEP |
| **9:15** | **General Session** - Salon I | |
| | Services to Children with Deaf-Blindness Program: An Update | Severe Disabilities Branch, OSEP<br><br>Dawn Hunter<br>Charles Freeman<br>Sara Conlon |
| **2:00** | **Lunch (No Host)** | |
| **1:30** | **Presentations** - Salon I | |
| | American Foundation for the Blind | Jeanne Prickett<br>Terry Rafalowski Welch |
| | Helen Keller National Center: Technical Assistance Center | Jane Everson |
| | National Information Clearinghouse for Children with Deaf-Blindness | John Reiman |
| | National Census for Children with Deaf-Blindness | Vic Baldwin |
| **3:30** | **Optional Information Session** - Salon I | |
| | National Coalition on Deaf-Blindness | Mike Collins |
| **3:30** | **TRACES Staff with State/Multi-State Projects** | |
| **5:30** | **TRACES Sponsored Social** - Consulate Room | |

## Tuesday, October 27, 1992

### All Projects Under Severe Disabilities Branch

| | | |
|---|---|---|
| 8:00 | **Coffee & Pastries** - Salon I | |
| 9:00 | **OSEP Staff Address** - Salon I | Judy Schrag, Director<br>Office of Special<br>Education Programs<br><br>Dawn Hunter, Chief<br>Severe Disabilities<br>Branch, OSEP |
| 9:30 | **Keynote** - Salon I | |
| | Things That Can Happen When Persons With Developmental Disabilities Get Arrested...A Journalist's View | Robert Perske |
| 10:30 | **Break** | |
| 11:00 | **Presentation** - Salon I | |
| | Technology Related Assistance for Individuals with Disabilities Projects | M. Nell Bailey<br>RESNA Technical<br>Assistance Project |
| 12:00 | **Lunch (Provided)** - Salon II | |
| 1:30 | **OSEP Staff Address** - Salon I | Dawn Hunter, Chief<br>Severe Disabilities<br>Branch, OSEP |
| 2:00 | **Sessions Specific to Categories of Funding** | |
| | See Separate Program Schedule for Category Identifications and Locations of Sessions | |
| 3:30 - 5:00 | **Poster Session** - Salon III | |
| 4:00 | **No Host Social** - Salon III | |

## Wednesday, October 28, 1992

### All Projects Under Severe Disabilities Branch

| | | |
|---|---|---|
| **8:00** | **Coffee & Pastries** - Salon I | |
| **9:00** | **Presentation** - Salon I | |
| | Winners All: A Call for Inclusive Schools | Virginia Roach<br>National Association for<br>State Boards of Education |
| **10:00** | **Break** | |
| **10:15** | **Presentation** - Salon I | |
| | Overview of Part H Activities | Early Childhood Branch, OSEP<br><br>Peggy Cvach<br>Ray Miner<br>Bobbi Stsettner-Eaten<br>Nancy Treusch |
| **11:30** | **Lunch (Provided)** - Salon II | |
| **1:00** | **Concurrent Presentations on Effective Practices - Section 1** | |
| | See Separate Program Schedule for Titles<br>and Locations of Presentations | |
| **1:45** | **Break** | |
| **2:00** | **Concurrent Presentations on Effective Practices - Section 2** | |
| | See Separate Program Schedule for Titles<br>and Locations of Presentations | |
| **3:00** | **Presentation** - Salon I | |
| | OSERS Future Initiatives | Patty Guard<br>Office of Assistant<br>Secretary, OSERS |
| **4:00** | **Adjournment** | |